

A community-based HIV stigma reduction and wellness enhancement intervention for people living with HIV and their partners

**MH Louwrens
12565318**

Dissertation submitted in fulfillment of the requirements for the degree *Magister Curationis* in Nursing at the Potchefstroom Campus of the North-West University

Supervisor: Prof M Greeff
Co-Supervisor Dr ME Manyedi

May 2014

TABLE OF CONTENTS

LANGUAGE EDITOR'S DECLARATION	v
TURN-IT-IN REPORT.....	vi
LIST OF ABBREVIATIONS	viii
RESEARCH OUTLINE.....	ix
ACKNOWLEDGEMENTS	x
AUTHOR'S CONTRIBUTION	xi
SUMMARY	xii
OPSOMMING	xiii
SECTION A: OVERVIEW OF THE RESEARCH	1
1 Introduction and Problem Statement	1
2 Research Objectives	6
3 Paradigmatic Perspective	6
3.1 Meta-theoretical assumptions	7
3.1.1 Person.....	7
3.1.2 Environment.....	7
3.1.3 Health.....	8
3.1.4 Illness	8
3.1.5 Nursing	8
3.2 Theoretical statements.....	9
3.2.1 Central theoretical argument	9
3.2.2 Conceptual definitions	9
3.3 Methodological statements.....	10

4	Research Methodology	11
4.1	Literature review	11
4.2	Research design	12
4.3	Research method.....	12
4.3.1	Phase 1: A holistic multiple case study of the community-based HIV stigma reduction intervention with PLHA and their partners	12
4.3.2	Phase 2: Qualitative interpretive description of the lived experiences of PLHA and their partners during and after the community-based HIV stigma reduction intervention	17
4.3.3	Data-analysis.....	19
5	Trustworthiness	20
6	Ethical Considerations	21
6.1	Quality of the research	21
6.2	Consent	22
6.3	Benefits and risks	22
7	Summary	22
8	References	23
	SECTION B: LITERATURE REVIEW	27
1	Introduction.....	27
2	The Impact of HIV and AIDS.....	28
3	Stigma in Context	29
3.1	Stigma definition.....	30
3.2	Stigma models	32
4	The Stigma Process	33

4.1	Triggers of stigma	33
4.2	Stigmatising behaviour	34
4.3	Stigma types	34
4.4	Stigma outcomes.....	36
5	HIV and AIDS Stigma Reduction Interventions	38
5.1	General interventions	39
5.2	Community-based interventions	41
5.3	Interventions with partners of PLHA.....	43
6	Urban and Rural Differences in HIV Stigma Experiences	45
7	Conclusion	45
8	References	46
SECTION C: ARTICLE		52
Guidelines for Africa Journal of Nursing and midwifery.....		53
SECTION D: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS.....		81
1	Conclusions	81
2	Limitations.....	82
3	Recommendations.....	83

LIST OF APPENDIXES

APPENDIX A: ETHICAL APPROVAL FOR THE STUDY	84
APPENDIX B: CONSENT TO BE A RESEARCH PARTICIPANT.....	85
APPENDIX C: EXAMPLE OF A NAÏVE SKETCH	88
APPENDIX D: EXAMPLE OF A FIELD NOTE	89
APPENDIX E: SECTION OF AN IN-DEPTH INTERVIEW	91

LIST OF TABLES

Table 1: Standards, strategies and criteria to ensure trustworthiness.....	20
---	-----------

LANGUAGE EDITOR'S DECLARATION

14 November 2013

To whom it may concern

I, Elma de Kock (ID 680910 0327 087, cell 083 302 5282), edited the dissertation entitled **A community-based HIV stigma reduction and wellness enhancement intervention for people living with HIV and their partners** by M.H. Louwrens.

Kind regards

A handwritten signature in black ink, appearing to read 'Elma de Kock', is written over a horizontal line.

Elma de Kock

TURN-IT-IN REPORT



Your digital receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

Paper ID	346456561
Paper title	12857734:2013-08-22TURN-IT- IN_LITERATURE_STUDY_MAXIE_Revised_by_Dr_Chigeza.docx
Assignment title	MAXIE RESUBMISSION AFTER CHANGES
Author	CARLIEN KAHL
E-mail	12857734@nwu.ac.za
Submission time	22-Aug-2013 10:00AM
Total words	7233

First 100 words of your submission

1. INTRODUCTION According to Holzemer et al. (2007:541) stigma has been acknowledged as a major confounding problem in the HIV and AIDS pandemic. UNAIDS (2008:8) described factors below as that which contribute to HIV and AIDS-related stigma. Firstly HIV and AIDS is a life-threatening disease and for that reason people react to it in strong ways. Secondly, HIV infection is linked with behaviours such as homosexuality, drug addiction, prostitution or promiscuity that are already stigmatised in numerous societies. Thirdly, majority of the people become infected with HIV through sex which often carries moral baggage. The fourth factor is that, there is a lot of incorrect information about how...

Copyright 2013 Turnitin. All rights reserved.

Turn-it-in (TII) process notes

Document submitted	eFundi site submitted through	Date of submission	% similarity on TII report	Comment/ motivation by supervisor or co-supervisor	Signature supervisor
Literature study	AUTHeR	2013-04-16	71%	Due to high percentage overlap/similarity, revisions needed to re-formulate original source into own words. All similarities were accurately references, but student didn't integrate source into own language and word order is too similar to sources.	
Literature study: re-submission	AUTHeR	2013-08-22	44%	Restructuring of sentences to re-formulate working of similar section was completed.	
Literature study: re-submission	AUTHeR	2013-08-22	22%	Final revisions to literature study made: sources that were changed were excluded. Result is satisfactory.	

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
NGO	Non-Governmental Organization
NWU	North-West University
PLHA	People living with HIV and AIDS

RESEARCH OUTLINE

The research is presented in an article format and includes the following:

Section A: An overview of the research

The purpose of the overview is to provide a brief literature review that led to the study, the paradigmatic perspective and a comprehensive overview of the planned research. More detail is provided here than possible in the article in section C.

Section B: Literature review

The purpose of the literature review is to present a critical synthesis of aspects that best support the case study and interpretive description approach. The literature review allows for a critical reflection on what literature does and does not contain, commentary on the strengths and weaknesses within the overall body of knowledge, as well as identifying gaps in the knowledge base.

Section C: The article

The article reports on the findings of the research.

ARTICLE TITLE	JOURNAL SUBMITTED TO
A community-based HIV stigma reduction intervention for people living with HIV and their partners	Africa Journal of Nursing and Midwifery

Section D: Conclusions, limitations and recommendations

This section presents the overall conclusions, limitations of the study discussed and recommendations for further research presented.

ACKNOWLEDGEMENTS

My gratitude is conveyed towards the following people, without whom I would not have been able to complete this study:

My ALMIGHTY GOD that blessed me indeed. He enlarged my frame of reference by making me part of this project.

The SANPAD Project for the bursary and financial support to conduct the research.

Prof. Dr. M. Greeff, my study leader, for her leadership, guidance and support throughout the study. She builds lighthouses, brings hope and encourages and always gives new perspectives.

Dr. M.E. Manyedi, my co-study leader, for guiding and supporting me and for sharing her expertise.

My family for their support and love.

Poncho Molaudzi, the research assistant, for her hard work during this project, as well as the experiences she shared during the intervention.

Mr. Motlhasedi, thank you for sharing your experiences and endurance.

Dr D.G. Anderson who's treatments enabled me to do far more than I expected.

Carlien Kahl for all her help and support.

Dr. Chigeza for support by reading through the literature review.

Heleen French for her encouragement throughout this study.

The participants of this study for sharing their experiences and taking part in the intervention.

Mediators and fieldworkers in this project for assistance to reach the participants.

Language editing: Mrs. E. De Kock

Lecturers of North-West University, Potchefstroom Campus, especially for Dr. P. Bester and Prof. C van der Walt for their support.

AUTHOR'S CONTRIBUTION

This study was planned and carried out by a team of researchers in AUTHeR (African Unit for Transdisciplinary Health Research) and an international collaborator from Vrije Universiteit. Each researcher's contribution is listed in the table below:

Mrs. M.H. Louwrens	M.Cur. student, responsible for the literature study, participating in the intervention with PLHA and partners and writing the text on people living with HIV and their partners.
Prof. Dr. M. Greeff	Supervisor, project leader, researcher and critical reviewer of this study.
Dr. M.E. Manyedi	Co-supervisor, member of the research team and critical reviewer of this study.

The following statement is a declaration by the author and co-authors to confirm their role in the study and to agree that it may be submitted in the article format as a dissertation.

Title: A community-based HIV stigma reduction and wellness enhancement intervention for people living with HIV and their partners

Declaration

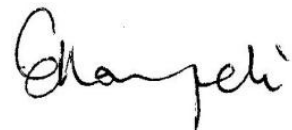
I hereby declare that I have approved the inclusion of one (1) article mentioned above in this dissertation and that my role in this study complies with what is described above. I hereby give consent that this article may be published as part of the M.Cur. dissertation of Mrs. Margaritha Hendriena Louwrens.



Mrs. M.H. Louwrens



Prof. Dr. M. Greeff



Dr. M.E. Manyedi

SUMMARY

The positive diagnosis of HIV impacts the lives and the relationships of both people living with HIV and AIDS (PLHA) and their partners. This could be the result of the PLHA experiencing stigmatisation from the side of his or her partner, or associated stigmatisation experienced by the partner due to living with the PLHA. The literature review makes it clear that limited research has been conducted on interventions to reduce HIV stigma in PLHA and their partners and this subsequently forms the focus of this study.

The study describes the effect of a community-based HIV stigma reduction intervention on PLHA and their partners through a case study method. In addition, it explores and describes the lived experiences of these two groups during and after an intervention in both an urban and a rural setting of the North West Province, South Africa.

A qualitative holistic multiple case study design and interpretive descriptive approach through in-depth interviews was used to implement and evaluate the intervention. Purposive voluntary sampling was conducted to access PLHA, and snowball sampling to reach their partners. The case record included multiple sources. Document analysis and open coding was used for analysis of the case records and open coding for the in-depth interviews.

No real differences were noted between the urban and rural groups. It was evident from both the case study and the expressed experiences of participants that the intervention was successful. Follow-up interventions with PLHA and partners are suggested, as well as implementations that involve other cultural groups in other provinces of South-Africa. Such implementations could be useful to evaluate the sustainability of the intervention in various cultural groups. The intervention could further be included in educational programmes offered in health care settings or NGO's to nurses, health care workers and volunteers to train people in HIV-stigma reduction programmes.

Keywords: AIDS; Community-based; HIV; Intervention; Partner; Stigma

OPSOMMING

Na die positiewe diagnose van MIV, word die lewens van die MIV-positiewe persoon sowel as die van die lewensmaat beïnvloed. Onderlinge verhoudinge, veral met die lewensmaat, word ook hierdeur beïnvloed. Stigmatisering deur die lewensmaat self of die geassosieerde stigmatisering wat die lewensmaat beleef as gevolg van assosiasie met die persoon wat die MIV virus lewe, kan die oorsaak daarvan wees. Tydens die literatuurstudie het dit duidelik geword dat beperkte navorsing gedoen is oor intervensies om die MIV stigma vir persone met MIV en hulle lewensmaats te verminder, en dit vorm gevolglik die fokus van hierdie studie.

Die doel van die studie was om die effek wat 'n gemeenskapsgebaseerde MIV-stigma verminderingintervensie het op mense wat leef met MIV en hulle lewensmaats deur 'n gevallestudiemetode te beskryf. Verder word beide groepe se belewenisse tydens en na die intervensie verken en beskryf in beide 'n stedelike en landelike gebied in die Noordwesprovinsie, Suid-Afrika.

'n Kwalitatiewe holistiese meervoudige gevalstudie-ontwerp en 'n kwalitatiewe interpreterende beskrywende benadering deur in-diepte onderhoude is gebruik om die intervensie te evalueer. Doelgerigte steekproefneming is gebruik om persone wat met MIV leef te bereik, en sneeubal-steekproefneming is gebruik om hulle lewensmaats te nader. Die gevalrekord het bestaan uit verskeie bronne. Die data is ontleed deur van dokumentanalise en oop kodering gebruik te maak.

Die stedelike en landelike gebiede het geen opsigtelike verskille getoon nie. Beide die gevalstudie sowel as die verbalisering van belewenisse deur deelnemers het getoon dat die intervensie wel suksesvol was. Opvolg intervensies met die persone wat leef met MIV en hulle lewensmaats word aanbeveel, asook verdere intervensies met ander kultuurgroepe in ander provinsies in Suid-Afrika om die volhoubaarheid van die intervensie te toets. Hierdie intervensies kan ook ingesluit word in opvoedkundige programme wat aangebied word in gesondheidsentra en nie-regering organisasies aan verpleegkundiges, gesondheidswerkers en vrywilligers om sodoende persone te bemagtig in programme vir MIV-stigmavermindering.

Sleutelwoorde: VIGS; Gemeenskapsgebaseerd; MIV; Intervensie; Lewensmaat; Stigma

SECTION A: OVERVIEW OF THE RESEARCH

The discussion that follows gives an overview of the study, the paradigmatic perspective and the planned research in more detail than is possible in the article.

The article that follows discusses the completed research and findings, and follows the guidelines prescribed by the Africa Journal of Nursing and Midwifery.

This study is embedded in and funded by the SANPAD Project: A Comprehensive Community-based HIV-stigma reduction and wellness enhancement intervention (Reference number: 09/15) with Prof. Dr. M. Greeff as project leader.

Acknowledgement is conveyed to SANPAD for the bursary and financial support received to conduct the research.

Keywords: AIDS; Community-based; Intervention; HIV; Partner; Stigma

1 Introduction and Problem Statement

This study is part of a bigger comprehensive community-based HIV stigma reduction and wellness enhancement intervention study. The focus of this study is on the intervention and the experiences during and after the intervention of people living with HIV (PLHA) and their partners. In this study partners refer to persons that are closely related and associated with PLHA and could be a spouse or boyfriend/girlfriend of a married or unmarried PLHA.

According to the global summary of the HIV and AIDS epidemic released by the World Health Organization and UNAIDS in December 2008, the number of people who were living with HIV in 2008 was 33,4 million. More than two-thirds of those were living in sub-Saharan Africa, and AIDS were the leading cause of death in this region (UNAIDS, 2008:1). The HIV pandemic is global, affecting people's quality of life (Greeff *et al.*, 2010:476). Stigma and discrimination continue to affect those living with and affected by HIV, particularly in South Africa (Greeff *et al.*, 2010:476). Holzemer *et al.* (2007:542) state the following regarding AIDS-related stigma: "AIDS stigma continues to affect people living with and affected by the HIV disease and their health care providers,

particularly in regions where HIV and AIDS are widespread, such as in South Africa. Stigma has emerged as a major barrier to HIV and AIDS care, as well as to primary and secondary prevention". Varaz-Diaz *et al.* (2005:169) found in their study that stigma further led to participants reporting in their study a loss of social support, persecution, isolation, job loss as well as the already mentioned problem of accessing healthcare services. The experience of stigma is painful and difficult for PLHA as well as for spouses, children and family who are often stigmatised through their association with PLHA (Greeff & Phethlu, 2007:23).

According to Holzemer *et al.* (2007:542) a significant percentage of the literature on HIV and AIDS stigma is primarily testimonial and provides support for negative effect of stigma on people's lives. This research group conducted a six year study on HIV and AIDS stigma in Africa. As part of this study a conceptual model focussing on the process of HIV and AIDS stigma was conceptualised (Holzemer *et al.*, 2007:541). The model identifies a set of three contextual factors that influence the stigma process, namely, environment, healthcare setting and agents. The stigma process articulates as a four-part interactive process, triggers of stigma, stigmatising behaviours, types of stigma (internal, received and associated stigma) and stigma outcomes.

Stigma has been defined by various authors, but is mainly seen as an attribute that discredits or devalues individuals who process it. It is increasingly interpreted as a socially constructed process based on the identification by society of certain personal characteristics or attributes as "different" and highly undesirable (Parker & Aggleton, 2003:17; Siyam'kela, 2003:13). An HIV-positive status is seen as highly undesirable, and as a result PLHA are labelled and set apart from the larger community (Holzemer & Uys, 2004:167). Uys *et al.* (2005:20) have described a wide range of words and phrases used in Southern African communities to name the disease, most of which have negative implications. The frequency of such negative labels supports the development of a rationale for devaluing, avoiding, rejecting, and excluding PLHA (Link & Phelan, 2001:385).

Closely linked to the experience of stigma is the experience of discrimination. Discrimination always follows stigma (Link & Phelan, 2002:4). Kohi *et al.* (2006:404) report that stigma and discrimination associated with HIV and AIDS are universal,

occurring in every country and region of the world. Stigma is influenced by many factors, such as lack of understanding of the disease, myths about how HIV is transmitted, and lack of appropriate treatment.

As seen in the model described by Holzemer *et al.* (2007:546) and other findings of other researchers, stigma affects both PLHA and those closely living and working with them. The focus of this study is on PLHA and their partners. The stigma attached to people living with HIV and AIDS affects both men and women, though the latter seem to be more stigmatised. In communities that have gender stereotypes, the problem may be so serious that women suffering from and suspected to be suffering from HIV and AIDS are sentenced to death. To cite but a few examples, in 1998 the worst scenario of gender discrimination and stigmatisation occurred when Gugu Dlamini, a female AIDS activist was killed in Kwa-Zulu Natal Province of South Africa following her public disclosure of her HIV-positive status (Brown *et al.*, 2003:51). Stein (in Manyedi 2007:3) discovered that a Muslim woman was sentenced to death because she disclosed her status after becoming aware that her dead husband had infected her with HIV. Owen (2002:70) confirms that in Asia such women have to cope with the additional burden of being chased away by their in-laws who become violent against them because their husbands had died of AIDS (Manyedi, 2007:3).

Sikkema *et al.* (2000:613) report on coping strategies and emotional wellbeing among HIV-infected men and women experiencing AIDS-related bereavement. Kittikorn *et al.* (2006:1292) report that coping with AIDS-related stigma has been identified as a major social concern worldwide. The wives of men with AIDS and members of other families where women had AIDS felt ashamed because of the stigma attached to the disease. They were considered by society to have deviated from the traditional, normative expectation of good women. The suffering of these women came from the fact that their daughters, and/or they, became stigmatised within the prevailing discourses regarding AIDS. They had no ability either to speak for their own rights or to resist this social stigma, because they had already evaluated themselves negatively and felt prejudged by society (Casseus, 2008:15). As the HIV epidemic continues to spread around the world, it is important not only to look at the disease itself, but at the related issues of AIDS stigma and its consequences within the local cultural context (Dlamini *et al.*, 2007:390). Greeff *et al.* (2010:483) found in their research that PLHA who reported

having disclosed their status to a friend, had a higher average life satisfaction score. Dlamini *et al.* (2007:389) further report on the verbal and physical abuse and neglect people suffer as a result of stigma. Link and Phelan (2006:528) mention that as a result of stigma, PLHA are denied access to the good things in life and suffer disproportionately from bad things, creating a source of chronic stress that exerts negative effects on both mental and physical health.

HIV and AIDS stigma does not only affect the PLHA, but also those close to them, including their family members, relatives, friends and caregivers. The most stigmatised family members seem to be the spouses, because of their perceived sexual relationship with the affected person (O'Sullivan & Thomson, and Nord in Manyedi, 2007:3). The present study is based on intervention research as a possible solution to the devastating effects of HIV stigma, with a specific focus on a community-based intervention aimed at PLHA and their partners.

Naidoo *et al.* (2007:23) report in their study the existence of urban and rural differences of HIV-stigma experiences of PLHA and nurses from five African countries. In general Naidoo *et al.* (2007:23) found that urban groups described more incidents of stigmatisation and discrimination than did the rural groups. It might be argued that urban discussion groups express themselves more fluently and are more confident with researchers. However, the groups in rural areas were as keen to discuss their experiences and seemed as forthcoming in describing incidents. The results suggest that stigma in all forms is received more often in urban areas than in rural areas, and that PLHA in urban areas as compared to rural areas are more active in self-stigmatisation. Their findings contradict the results of some other researchers, who found that the HIV-related stigma was relatively more frequent in rural areas. Naidoo *et al.* (2007:22) propose that several factors relating to greater social networks and socio-economic influences could be attributed to such patterns.

Several HIV-stigma reduction programmes, workshops and interventions have been launched in Africa. The interventions mostly aim to share information on HIV and AIDS, increasing an understanding of HIV stigma, human rights, advocacy, gender, violence, the workplace, disclosure, dealing with HIV stigma, relationships and communication with others, strengthening the position or coping of the PLHA, as well as how health

care professionals should respond to stigma (Greeff, 2009:2). The majority of the studies as reviewed by Brown *et al.* (2003:49) tested a variety of interventions to decrease AIDS stigma in developed and developing countries, one in Thailand and the rest in Africa. The majority of the studies aimed to increase tolerance of PLHA among the general population. The remainder of the studies tested interventions to increase the willingness to treat PLHA among health care providers to improve coping strategies for dealing with the AIDS stigma among PLHA or at-risk groups. Results suggest that some stigma reduction interventions appear to work, at least on a small scale and in the short run, but this is inadequate, especially in relation to the scale and duration of the impact of stigma reduction intervention. They categorised the interventions in these studies as either one of four types: Information-based approaches; Skills building; Counselling approaches; and Contact with affected group (Greeff, 2009:3).

Uys *et al.* (2009:1059) in their study, “The Perceived AIDS stigma: A multinational African study”, did a pilot testing of a service-based stigma reduction intervention. The intervention was grouped in five settings in different countries in Africa and focussed on the cooperation between nurses and PLHA in a stigma reduction intervention. They combined three strategies: sharing information; increasing contact with the affected group; and improving coping through empowerment. Their data suggested that this intervention was very effective in reducing the perceived HIV stigma experienced by PLHA. Although some studies have examined stigma and disclosure of PLHA, there are not many studies concerning a community-based intervention for stigma reduction and wellness enhancement for PLHA and their partners. Manyedi in 2007 examined the coping strategies with stigma of women whose partners died of AIDS. According to Jullianne *et al.* (2006:70) the purpose of their study was to investigate the reasons HIV positive gay men proposed for disclosing or not disclosing their sero-status to their casual partners. Valerian *et al.* (2002:415) studied the perceived HIV-related stigma after finding out about the sero-positive diagnosis and after the disclosure to relationship partners. Padilla *et al.* (2008:380) studied stigma, social inequality, and HIV risk disclosure among Dominican sex workers.

My personal experiences as a midwife working with couples where HIV is a factor, has confirmed the experiences reported in the literature. The literature review showed that the positive diagnosis mostly has a negative impact on the relationship between the

PLHA and the partner. This is a result of the associated stigmatisation of the partner, as well as stigmatising from the PLHA *per se*. Through the literature review it became obvious that limited research has been conducted on community-based interventions to reduce stigma in HIV in PLHA and their partners. The focus of this intervention study with PLHA and their partners will address the paucity in this field.

Based on the problem as explained above, the following questions arise:

- In what way can a community-based HIV stigma reduction intervention reduce stigma in PLHA and their partners in an urban and a rural setting in the North West Province?
- What are the experiences of PLHA and their partners during and after a community-based HIV stigma reduction intervention in an urban or a rural setting in the North West Province?

2 Research Objectives

Based on the above-mentioned research questions and problem statement the researcher aims to:

- Describe the effect of a community-based HIV stigma reduction intervention on PLHA and their partner by means of a case study method in both an urban and a rural setting in the North West Province.
- Explore and describe the lived experiences of PLHA and their partners during and after a community-based HIV stigma reduction intervention in both an urban and a rural setting in the North West Province.

3 Paradigmatic Perspective

The paradigmatic perspective of this study reflects the view of the researcher on a meta-theoretical, theoretical and methodological level. The worldview of the researcher

is based on a Christian Reformed religion that is grounded on the Bible, Kurt Goldsteins' self-actualization theory (Sadock & Sadock, 2003:221), John Hollands' theory of personal types (Louw *et al.*, 2002:444) and a nursing theory that is based on a Judeo-Christian philosophical foundation. This has been developed at the Anna Vaughn School of Nursing of the Oral Roberts University (1990) and is called the "Nursing for the Whole Person Theory."

3.1 Meta-theoretical assumptions

The meta-theoretical assumptions of this study are grounded on the researcher's own philosophy that respects the uniqueness of every person, their dignity, beliefs and value systems, as well as their culture. The meta-theoretical assumptions of this study comprise the concepts person, environment, health, illness and nursing.

3.1.1 Person

The researcher believes that a person is a total biological, psychological, spiritual and social being. Man is created in the image of God. A person's psyche consists of her or his thoughts, volition and emotions. In this study person refers to both the PLHA and the partner.

3.1.2 Environment

The environment is internal as well as external and comprises all those forces that influence a person at any given time during a lifetime. The internal environment comprises all those forces that are from within namely physical, social, spiritual and psychological factors, including values, beliefs and morals. An external environment comprises external forces namely physical, social, psychological and spiritual factors. All these forces influence the person either positively or negatively. When the environmental forces are positive, an individual's reaction is positive and when negative, the individual's reaction may also be negative, leading to ill health. Every person is unique in the manner that they react to stimuli within their environment, the way they think, as well as their beliefs and values. Persons react to the environment based on their previous experiences. Every person is, therefore, in constant interaction with his or her environment, which may be internal or external.

3.1.3 Health

Health is a state of wholeness and includes the continuum of health and illness. An individual is in a state of health when there is absence of disease and life stressors that lead to stress. The individual, however, has the potential to become ill. Wholeness is maintained when an individual interacts positively with his or her environment. Every individual is responsible for his or her own health.

3.1.4 Illness

Illness is a dynamic state that reflects the nature of the person's interactive patterns of stressors in his internal and external environment. Illness can be qualitatively described on a continuum from severe illness to minimum illness. Health potential does exist in those who are ill. When an individual fails to maintain his or her health, he or she may seek the intervention of the health professionals. In the context of this research, the stigmatisation of people living with HIV and AIDS and their partners interferes with their health status.

3.1.5 Nursing

Nursing is a belief in the essential worth of every human life and in the divine reason for the existence of this life; it is a belief in the uniqueness and irreplaceability of every human being and it is a belief that the Creator charged humankind with the serious responsibility for her or his own personal well-being and for the well-being of the rest of humankind. Nursing implies faith in a continuous source of inner strength that assists us in doing what is expected of us, and that guides our behaviour. Nursing is a yearning to be a worthy servant of humanity and an effective instrument of health science. Nursing requires acceptance of the fact that every human being is unique, acceptance of the need to employ all health aids to provide for the health needs of this unique being: it is acceptance of the fact that there really are no patients and that disease viewed as a separate entity really does not exist, but that there are only sick people or people with health needs. It is acceptance of the fact that nursing consists not only of a series of tasks that have to be performed or a set of procedures that have to be followed, but that it is a professional service to humankind that includes instrumental and expressive functions. Nursing transcends the so-called nurse-patient relationship to make it a

human being-to-human being relationship. Nursing is conservation and change – the conservation of the precious human life through change, for nursing seeks to prevent, promote, to reverse or to balance in order to conserve. Nursing is assistance and support, not only to those who are dependent on the health staff, but also to those who render the service. In its application of scientific skills during the treatment and the care of the human being, and as such it is a technology. Nursing is the therapeutic use of the self; it is love that is made visible. The nurse plays the role, instils confidence and trust in the patient and creates a counselling, helping, supporting and empathic relationship with the patient, determines how the patient will use her support in the struggle for improved health and whether he will begin to take responsibility for the struggle to regain or improve health. Nursing is regarded as a goal-directed service, which is directed towards assisting the individual, family and the community to promote, maintain and restore health.

3.2 Theoretical statements

The theoretical statement for this study comprises the central theoretical argument and conceptual definitions as discussed below.

3.2.1 Central theoretical argument

The impact of stigma on both PLHA and their partners through stigma triggers causes stigmatising behaviour that leads to negative stigma outcomes. The experiences of the stigma process influence the relationship between the parties, as well as their community and health centres. The understanding of stigma, enhancement of the relationship between the PLHA and the partner and doing a project together will empower both PLHA and their partners to become leaders in the community to reduce HIV stigma.

3.2.2 Conceptual definitions

See also partner and stigma as defined in the introduction.

3.2.2.1 Intervention

“Interventions are defined as treatments, therapies, procedures, or actions implemented by health professionals to and with clients, in a particular situation, to move the client’s condition toward desired health outcomes that are beneficial to the clients” (Sidani & Braden, 1998:8 in Burns & Grove, 2005:28). Burns and Grove (2005:29) refer to an intervention as a specific treatment implemented to manage a well-defined patient problem or a program. In this study the term intervention refers to the community-based HIV-stigma reduction and wellness enhancement intervention that was conducted with PLHA and their partners in both an urban and a rural setting.

3.2.2.2 Community-based

A community is a group of people who share some type of bond, who interact with each other, and who function collectively regarding common concerns (Clark, 1999:5). This study is based on an intervention in the community with the aim to reduce HIV stigma and enhance emotional wellness of PLHA and their partners. Lippman (2009:8) explains community interventions as interventions that intend to change the community context and to create an enabling environment in which people can make healthy choices. Prevention messages and strategies in community-based programmes that include the social context are as much focused on informing individuals as they are intended to impact community social norms and community social forces and the structures that keep norms in place. The focus in this study is on the PLHA and their partners within a community context.

3.3 Methodological statements

The researcher supports the research model of Botes (1994:36–42). The application of the Botes model (1994:6-22) in conducting the research can increase its validity and reliability, since the model is specifically developed for nursing research. The functional reasoning approach, which is the framework of this model, advocates that research should lead to the development of theories that serve to improve the nursing practice (Botes, 1994:37). Research activities as presented within this model are arranged on three levels/orders in accordance with the practical aim of the research. The first level or order represents the *practice of nursing*, which forms the research domain for nursing.

The practice level of this research is the context of HIV stigma in urban and rural communities.

The first level leads to the second level in which *research and theory development* takes place. Ultimately, in accordance with Botes' theory (Botes, 1994:39), the practical usefulness of this research served as a criterion for its internal validity. In this research the qualitative case study strategy (Yin, 2009:40) and qualitative interpretive descriptive approach (Thorne, 2008:25) guided the researcher in studying the phenomenon of HIV stigma reduction. The third level represents the *paradigmatic perspective* within which this research was undertaken:

- The meta-theoretical assumptions underlying the study refer to the researchers' view of person, environment, health and nursing.
- The theoretical assumptions refer to the central theoretical argument and conceptual definitions based on theory.

The methodological assumptions entail that the researcher approached the study using the qualitative research paradigms of both case study (Yin, 2009:3-24) and interpretive description (Thorne, 2008:50-51).

4 Research Methodology

The research methodology of this study follows the order discussed below, namely the literature study to contextualise HIV stigma in PLHA and their partners, the research design, the research method, trustworthiness and the ethical considerations.

4.1 Literature review

A detailed literature review was conducted to conceptualize HIV stigma in PLHA and their partners and to investigate the availability of interventions in this area. The following databases were used for both the initial literature review and the detailed literature review:

EbscoHost - Academic Search Premier, Cinahl, Health Source; Nursing Academic Edition, MasterFile, Medline, Psycinfo, ScienceDirect. International Thesis and Dissertations: ProQuest, Nexus. Other databases: Cochrane, World Wide Web.

4.2 Research design

A qualitative holistic multiple case study design (Yin, 2009:59) and interpretive description approach (Thorne, 2008:50) were used to describe a community-based HIV stigma reduction intervention on PLHA and their partners as well as to explore and describe PLHA and their partners' lived experiences during and after having undergone the intervention in both an urban and a rural setting in the North West Province.

4.3 Research method

Two phases characterise the research method through which this study will be conducted.

4.3.1 Phase 1: A holistic multiple case study of the community-based HIV stigma reduction intervention with PLHA and their partners

4.3.1.1 Sample

- **Population**

The population in this phase of the study will comprise of two groups of people: PLHA and their partners living in the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district (urban) and in the Bophirima district (rural) of the North West Province, South Africa.

- **Sampling**

For PLHA: Purposive sampling (Thorne, 2008:90) will be conducted. Ten to twelve PLHA from the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda urban district and 10-12 PLHA from the Bophirima district rural district will be identified (n=20-24).

The following inclusion criteria will be used

- Participants will have been diagnosed with HIV for at least 6 months.
- Participants will be above 18 years of age.
- Participants will be residents in the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district for the urban sample and the Bophirima district for the rural sample.
- Participants must be able to communicate in either Afrikaans or English and Setswana.
- Participants must be open and willing to share their experience in an in-depth interview.
- Participants must be willing to participate in the study and give consent to be audio-recorded.

For partners of PLHA: Snowball sampling (Burns & Grove, 2009:356) will be used to identify the partners of the PLHA. Each PLHA will be requested to bring a partner if they are presently actively involved in a relationship. Ten to twelve partners from the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda urban district and 10-12 partners from the rural Bophirima district will be identified (n=20-24).

The following inclusion criteria will be used:

- The participant will be a person, male or female living, or sharing life with PLHA or married to them.
- Participants will be above 18 years of age.
- Participants will be residents in the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district or the Bophirima district.
- Participants must be able to communicate in Afrikaans or English and Setswana.

- Participants must be open and willing to share their experience in an in-depth interview.
- Participants must be willing to participate in the study and give consent to be audio-recorded.
- Sample size

According to Yin (2009:58), the important consideration for the number of theoretical replications is related to your sense of the importance of rival explanations. The stronger the rivals, the more additional cases you might want, each case showing a different result when some rival explanation has been taken into account (Yin, 2009:58). According to Thorne (2008:94), the best way to justify a sample size is to generate a rationale that is consistent with the research question. How many instances of a phenomenon will be necessary for inclusion in our observations and analysis in order for the findings to have any merit to those for whom the research will be conducted? If the background literature and disciplinary wisdom suggests that a certain phenomenon occurs commonly within clinical populations and a more in-depth exploration of its underlying subjective experiential nature is needed, then the researchers can likely determine that engaging with a small number of individuals in experiments familiar with it who are willing to share that with the researchers, this might produce something worth documenting. Thorne (2008:98) suggest that smaller interpretive description studies are justified in having set arbitrary sample limits, as long as they show recognition that there would always be more to study.

4.3.1.2 Data collection

- **Method of data collection**

The case study method will be used to collect data during the community-based HIV stigma reduction and wellness enhancement intervention where each of the two settings (urban and rural) will form the cases.

- **Intervention**

A community-based HIV stigma reduction intervention will be presented to a specific group of urban and rural people living with HIV and their partners. The intervention with PLHA and their partners will be a three day workshop focusing on the underlying tenets:

- Increasing knowledge about HIV stigma and coping with it;
- Equalising the relationship between PLHA and the partner;
- Empowering PLHA and their partners to become leaders in their communities to reduce stigma.

The intervention will consist of a three day workshop structured into first a two-day workshop, after which participants will implement a project with other partners in this community for a month. This will be followed by the third day workshop to evaluate the success of the implementation of the project.

The workshop will follow a path of processes and activities that build knowledge and understanding of HIV stigma and how to cope with it, as well as promote interpersonal familiarity and trust through contact and sharing. Overall, a participatory approach focusing on mobilising participant participation, contact and collaboration will be employed. This will be accomplished using a range of participatory activities and focused inputs by the persons facilitating the process. The facilitators of the group will attend a training workshop beforehand.

- **Naïve sketches**

Evaluation will be performed at the end of every workshop day through naive sketches. Each participant will have the opportunity to reflect on the day and these will be collected for the case record. Each participant will get a sheet with two questions for completion of the naive sketch. Using the written comments of the participants, a general group discussion on evaluation will follow and the co-facilitator will record this discussion in minutes. “I experience the first day of the workshop” and followed by “I feel...”

- **Field notes**

Field notes will be written during and at the end of every workshop day by the facilitator and co-facilitator. The field notes will be divided into observational notes, methodology notes and personal notes. According to Yin (2009:85), with the preceding orientation in mind, the field notes of the protocol will need to emphasize the major tasks in collecting data, including:

- Gaining access to key organizations or interviews;
- Having sufficient resources while in the field – including a personal computer, writing instruments, paper, paper clips, and a pre-established, quiet place to write notes privately;
- Developing a procedure for calling for assistance and guidance, if needed, from other case study investigators or colleagues;
- Making a clear schedule of the data collection activities that are expected to be completed with specified periods of time; and
- Providing for unanticipated events, including changes in the availability of interviewees, as well as changes in the mood and motivation of the case study investigator (Yin, 2009:85).
- Case record

The case record will include a detailed description of the HIV-stigma reduction intervention, presentations and manual of the intervention, naive sketches of participants after each day of the intervention, field notes of the researchers during the intervention, a detailed description of the project of the two groups (urban and rural), as well as the project evaluation report.

- **Role of researcher**

Access to the community has been obtained through previous research, which has already built trust with the community in Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district (urban) and in Ganyesa as part of the Bophirima district

(rural), as well as with Non-Governmental Organizations (NGO's). Field workers will be used to link the researchers and research assistant with the prospective participants. A private, interruption-free and comfortable venue for the intervention will be arranged. In the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district (urban) it will be at the university, while in Ganyesa it will be at a guesthouse. During the first contact with prospective participants, the research assistant will explain the objectives of the research, ensure that participants know what is expected of them and what kind of data will be collected, and informed consent will be obtained. Transport to venues will be available for participants. Meals and refreshments will also be available during the intervention. Appointments will be confirmed a day before the workshops. Sensitive ethical issues that arise will be handled with integrity. Participants will be ensured that they can withdraw at any stage of the research and that their identities will be protected (Botma, *et al.*, 2010:203-204).

- Data-analysis

Each case will be analysed and then compiled. The various aspects of the case record will be made. The data obtained from the case record will be analysed using document analysis, pattern matching and cross-case synthesis (Yin, 2009:136).

4.3.2 Phase 2: Qualitative interpretive description of the lived experiences of PLHA and their partners during and after the community-based HIV stigma reduction intervention

4.3.2.1 Sample

The same sample as described under phase one will be used.

4.3.2.2 Data collection

- Method of data collection

A central element of data collection and analysis in interpretive description is that one is seeking the kind of knowledge that must be inductively generated from within the data and developed within the context of the data (Thorne, 2008:99). In this phase of data collection in-depth interviews will be used to gather the data from both PLHA and their

partners. During the in-depth interviews the following open-ended questions will explore how PLHA and their partners experienced the intervention.

To the PLHA: *“How did you experience the workshop and project with your partner and others in the group?”*

To the partners: *“How did you experience the workshop and project with the PLHA and others in the group?”*

Interviews will be tape-recorded. The tape recorder will be placed inconspicuously as it could distract the novice researcher and make the participant uncomfortable. The following are a few communication techniques mentioned by Okun in Botma *et al.* (2010:226) that will be utilised in interviews: Minimal verbal responses, listening, paraphrasing, reflecting, clarifying, probing, summarising, encouraging and acknowledging.

- Field notes

According to Botma *et al.* (2010:217), field notes are a written account of the things the researcher hears, sees, feels, experiences and thinks about in the course of the interview. During this study field notes will be written during and directly after the interview. Polit and Beck in Botma *et al.* (2010:218) provide a useful structure for reflective notes. Methodological notes, theoretical notes and personal notes.

- Role of the researcher

The same role as described under phase one will be applicable.

- Setting

The interviews will take place in the area most convenient for the participants. It could be in their private homes or in a private room at North-West University in Potchefstroom or in the conference room of a guesthouse in Ganyesa.

4.3.3 Data-analysis

In this study qualitative data will be transcribed and analysed using the eight steps of the open coding technique of Tesch (in Creswell, 1994:154-155). Tesch steps are as follows:

- Get a sense of the whole. Read all the transcriptions carefully. Jot down some ideas that come to mind.
- Pick one document (i.e. transcript of an interview) – the most interesting one, shortest one, the one top of the pile. Read through it, asking: “What is this about”? Do not think about the content, but look for the underlying meaning. Jot thoughts down in the same margin.
- Read through several participants’ data and do the same as in step 2. Now make a list of all the topics that come to mind. Form these topics into columns (maybe mayor topics, unique topics and leftovers).
- Now take this list of topics and go back to the data. Abbreviate the topics as codes and write codes next to the appropriate segments of the text. See if new categories and codes emerge.
- Find the most descriptive wording for your topics and turn them into categories. Look for ways of reducing your list of categories by grouping categories that relate to each other. Perhaps draw lines between categories to show interrelationships.
- Make a final decision on the abbreviation for each category and alphabetise these codes.
- Assemble the data belonging to each category in one place and perform a preliminary analysis.
- If necessary, recode your existing data (Botma *et al.*, 2010:224-225).

An independent co-coder will be used to analyse the data. A work protocol will ensure that the co-coder is aware of the purpose of the study, as well as the steps to follow for data analysis. Regular communication and meetings will be held with the co-coder.

Consensus discussions will be conducted to come to an agreement about the coding, categories and final themes.

5 Trustworthiness

The data collection process for case studies is more complex than those used in other research methods. A case study investigator must have a methodological versatility not necessarily required for using other methods and must follow certain formal procedures to ensure quality control during the data collection process. These procedures are intended to make the process as explicit as possible, so that the final results – the data that have been collected – reflect a concern for construct validity and for reliability, thereby becoming worthy of further analysis (Yin, 2009:124). The three principles are as follows: use multiple sources of evidence; create a case study database; and maintain a chain of evidence (Yin, 2009:122).

Rigour will be ensured in this research process by using the model of Guba and Lincoln (in Krefting, 1991:217; Klopper, 2008:70) to assess the trustworthiness of the quality data (see Table 1). Trustworthiness comprises truth-value, applicability, consistency and neutrality.

Table 1: Standards, strategies and criteria to ensure trustworthiness

Standards	Strategies	Criteria
Truth value	Credibility	<p>Prolonged engagement during intervention (workshop, project and interview).</p> <p>The researcher will consistently reflect on her experiences during the research through field notes, reflecting on the naive sketches and discussions with study leaders.</p> <p>Triangulations:</p> <p>Methods: Case study, Interview, field notes.</p> <p>Sources: Detailed case records and interviews.</p> <p>Investigator: Part of multi-disciplinary research team, study leaders.</p> <p>Interview technique: PLHA and Partner, post-intervention</p> <p>Authority of the researcher:</p>

		Professional Nurse working with PLHA and partners within an experienced research team.
Applicability	Transferability	Selection of sources or sampling: Purposive and snowball sampling Dense description of the case record and interview Saturation of data according to Thorns' approach Thick/dense description of the methodology.
Consistency	Dependability	Audit trail will be possible Stepwise replication: Possible due to dense description of the study Thick and dense description of the methodology Independent co-coder during data analysis
Neutrality	Confirmability	Confirmability audit: Audit trail will be possible. Triangulation (See truth value) Reflexivity (See truth value)

(Adjusted from Botma *et al.*, 2010:234-235).

6 Ethical Considerations

Ethics approval has been given for the comprehensive project for the period 30 March 2009 to 29 March 2014, NWU-00011-09-A1.

Ethical aspects were observed throughout this study as prescribed by the Democratic Nursing Organisation of South Africa (DENOSA) (1998:1-7), as well as according to Burns and Grove (2005:174).

6.1 Quality of the research

The researcher will maintain the highest standard of research through the accredited methodologies as recommended by the study leaders of this dissertation, as well as the literature. All procedures will be carried out with integrity as described below. The in-depth interview questions will be assessed by experts for validity, confidentiality and anonymity. All participants' identities will not be guarded at all times and throughout the research procedures. The names of participants are only revealed to the researcher,

her study leader and co-study leader. The privacy, personal worth and the dignity of the participants will be maintained. The researcher will make sure that there will be no linking of any participant's identity or organisation with the research data (DENOSA, 1998:1-7; Burns & Grove, 2005:172).

6.2 Consent

Permission to conduct research will be obtained from the Research committee of the School of Nursing Science, North-West University (NWU) Potchefstroom Campus, the Ethics Committee of the NWU, as well as the North-West Provincial Department of Health. The mediators will provide the researcher with the names, addresses and/or telephone numbers of prospective participants. Letters to request participation and give consent will be written to prospective participants to explain the research topic to them, the objectives of research, as well as the researcher's expectations of their role. They will also be informed about their voluntary participation, as well as their right to withdraw at any stage of the process. They will also be informed about the use of audio-tapes during interviews and the fact that confidentiality, anonymity and privacy were maintained throughout the process.

6.3 Benefits and risks

The researcher will ensure that participants are protected from discomfort and harm by counselling or debriefing them. The participants will also be free to discontinue their participation at any stage, had they experienced loss of interest in the process (Burns & Grove, 2005:175). All these ethical measures will be observed in order to obtain co-operation from the participants and all other parties in this study.

7 Summary

The overview described the introduction, the problem statement, research objectives, paradigmatic perspectives and research methodology. Section B will present an overview of the literature.

8 References

- Anna Vaughn School of Nursing. 1990. Self-study report: Submitted to the Council of Baccalaureate and Higher Degree Programs, National League for Nursing for the Oral Roberts University. *Narrative by criteria*, 136-142. Tulsa, Oklahoma.
- Botes, A. 1994. 'n Verantwoordbare navorsingsvoorstel. Johannesburg: Randse Afrikaanse Universiteit.
- Botma, Y., Greeff, M., Mulaudzi, M. & Wright, S. 2010. Research in health sciences. Cape Town: Heinemann.
- Brown, L., Macintyre, K. & Trujillo, L. 2003. Interventions to reduce HIV and AIDS stigma: What have we learned? *AIDS education and prevention*, 15(1):49-69. doi: 10.1521/aeap.15.1.49.23844
- Burns, N., Grove, S.K. 2005. The practice of nursing research. 5th ed. Missouri: Saunders.
- Burns, N. & Grove, S.K. 2009. The practice of nursing research: appraisal, synthesis and generation of evidence. 6th ed. St. Louis, Mo: Elsevier Saunders.
- Casseus, C. 2008. The diagnosis of HIV/AIDS as traumatic for Haitian women: an internet study exploring depression, stigmatization, social support, and any positive outcomes – toward a tailored model of care. Columbia: Columbia University (Thesis – PhD).
- Clark, M.J. 1999. Nursing in the community. 3rd.ed. Stamford: Appleton & Lange.
- Creswell, J.W. 1994. Research design: Qualitative and Quantitative approaches. London: SAGE.
- DENOSA (Democratic Nurses Organization of South Africa). 1997. Ethical standards for nurse researchers. Pretoria: DENOSA.
- Dlamini, P.S., Kohi, T.W., Uys, L.R., Phetlhu, R.D., Chirwa, M.L., Naidoo, J.R., Holzemer, W.L., Greeff, M. & Makoe, L.N. 2007. Verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma in five African countries. *Public health nursing*, 24(5):389-399. doi: 10.1111/j.1525-1446.2007.00649.x
- Greeff, M. 2009. A comprehensive community-based HIV stigma reduction and wellness enhancement intervention. (SANPAD research proposal, 15 September 2009. Reference number 09/15). (Unpublished).
- Greeff, M. & Phetlhu, R. 2007. The meaning and effect of HIV/AIDS stigma for people living with AIDS and nurses involved in their care in the North-West Province, SA. *Curationis*, 30(2):12-23. doi: 10.4102/curationis.v30i2.1066
- Greeff, M., Uys, L.R., Wantland, D., Makoe, L., Chirwa, M., Dlamini, P., Kohi, T.W., Mullan, J., Naidoo, J.R., Cuca, Y. & Holzemer, W.L. 2010. Perceived HIV stigma and

life satisfaction among persons living with HIV infection in five African countries: A longitudinal study. *International journal of nursing studies*, 47:475-486. doi:10.1016/j.ijnurstu.2009.09.008

Holzemer, W.L., & Uys, L.R. 2004. Managing AIDS stigma. *Journal of social aspects of HIV/AIDS*, 1(3):311-324.

Holzemer, W.L., Uys, L.R., Makoe, L., Stewart, A., Phetlhu, R., Dlamini, P., Greeff, M., Kohi, T.W., Chirwa, M., Cuca, Y. & Naidoo, J. 2007. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of advanced nursing*, 58(6):541-551. doi: 10.1111/j.1365-2648.2007.04244.x

Julianne, M., Serovich, K.E. & Mosack, K.E. 2006. Reasons for HIV disclosure or non-disclosure to casual sexual partners. *AIDS education and prevention: an interdisciplinary journal*, 15(1):70-80.

Kittikorn, N., Street, A.F. & Blackford, J. 2006. Managing shame and stigma: Case studies of female carers of people with AIDS in Southern Thailand. *Qualitative health research*, 16(9):1286-1301. doi: 10.1177/1049732306293992

Klopper, H. 2008. *The qualitative research proposal*. Curationis, 31(4):62-72.

Kohi, T.W., Makoe, L., Chirwa, M., Holzemer, W.L., Phetlhu, D.R., Uys, L.R., Naidoo, J., Dlamini, P.S. & Greeff, M. 2006. HIV and AIDS stigma violates human rights in five African Countries. *Nursing ethics*, 13(4):404-415. doi: 10.1191/0969733006ne865oa

Krefting, L. 1991 Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy*, 45(3):214-222. doi: 10.5014/ajot.45.3.214

Link, B.G. & Phelan, J.C. 2001. Conceptualising stigma. *Annual review of sociology*, 27:363-385.

Link, B.G. & Phelan, J.C. 2002. On stigma and its public health implications. <http://www.stigmaconference.nih.gov/FinalLinkPaper.html> Date of access: 22 August 2010.

Link, B.G. & Phelan, J.C. 2006. On stigma and its public health implications. *Lancet*, 367(9509):528-529. doi:10.1016/S0140-6736(06)68184-1

Lippman, S.A. 2009. Modifying the social environment for HIV and STI prevention: Evaluation of a multi-level, community-based intervention among sex workers in Brazil. Berkeley: University of California. (Dissertation – PhD).

Louw, D.A., van Ede, D.M. & Louw, A.E. 2002. Menslike ontwikkeling. 3rd ed. Cape Town: Kagiso Tiersier.

Manyedi, M.E. 2007. Coping with stigma by women whose partners died of AIDS. Potchefstroom: North-West University (NWU). (Thesis – PhD.).

Muller, M. 2002. Nursing dynamics. 2nd ed. South Africa: Heinemann.

Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoe, L., Dlamini, P., Phetlhu, R.D., Chirwa, M. & Kohi, T. 2007. Urban and rural differences in HIV/AIDS stigma in five African countries. *African journal of AIDS research*, 6(1):17-23. doi: 10.2989/16085900709490395

Owen, M. 2002. The plight of widows and AIDS. *Women's international network news*: 70, 1 Mar.

Padilla, M., Castellanos, D., Guilamos-Ramos, V., Reyes, A.M., Sanchez Marte, L.E. & Soriano, M.A. 2008. Stigma, social inequality, and HIV risk disclosure among Dominican male sex workers. *Social science & medicine*, 67(3):380-388. doi:10.1016/j.socscimed.2008.03.014

Parker, R. & Aggleton, P. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine*, 57:13-24. doi: [http://dx.doi.org/10.1016/S0277-9536\(02\)00304-0](http://dx.doi.org/10.1016/S0277-9536(02)00304-0)

Sadock, J.S. & Sadock, A.S. 2003. Synopsis of psychiatry. 9th ed. Philadelphia: Lippencott.

Sikkema, K.J., Kalichman, S.C., Hoffman, R., Koob, J.J., Kelly, J.A. & Heckman, T.G. 2000. Coping strategies and emotional wellbeing among HIV-infected men and women experiencing AIDS-related bereavement. *AIDS care*, 12(5):613-624. doi: 10.1080/095401200750003798

Siyam'kela. 2003. Siyam'kela measuring HIV/AIDS related stigma: A report on the fieldwork leading to the development HIV/AIDS stigma indicators and guidelines. Policy Project, South Africa: Centre for the Study of AIDS. University of Pretoria; United States Agency for International Development; Chief Directorate: HIV, AIDS, TB, Department of Health. <http://www.csa.za.org> Date of access 13 Nov. 2013.

Thorne, S. 2008. Interpretive description. California: Left coast press.

UNAIDS. 2008. Global summary of the HIV/AIDS epidemic. http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/globalreport/2008/jc1510_2008globalreport_en.pdf Date of access 13 Nov. 2013.

Uys, L.R., Chirwa, M., Dlamini, P., Greeff, M., Kohi, T., Holzemer, W., Makoe, L., Naidoo, J.R. & Phetlhu, R. 2005. Eating plastic, winning the lotto, joining the WWW: Descriptions of HIV/AIDS in Africa. *Journal of the association of nurses in AIDS care*, 16(3): 11-21. doi:10.1016/j.jana.2005.03.002

Uys, L., Chirwa, M., Kohi, T., Greeff, M., Naidoo, J., Makoe, L., Dlamini, P., Durrheim, K., Cuca, Y., Holzemer, W.L. 2009. Evaluation of a health setting-based stigma intervention in five African countries. *AIDS patient care and STDs*, 23(12):1059-66. doi:10.1089/apc.2009.0085

Valerian, J., Derlega, B.A., Winstead, K.G., Julianne, S. & William, N. 2002. Perceived HIV-related stigma & disclosure to relationship partners after finding out about the

seropositive diagnosis. *Journal of health psychology*, 7(4):415-432. doi: 10.1177/1359105302007004330

Varas-Diaz, N., Serrano-Garcia, I. & Toro-Alfonso, J. 2005. AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. *Qualitative health research*, 15(2):169-187. doi: 10.1177/1049732304272059

Yin, R.K. 2009. Case study Research. 4th ed. London: SAGE.

SECTION B: LITERATURE REVIEW

HIV STIGMA REDUCTION FOR PARTNERS OF PEOPLE LIVING WITH HIV AND AIDS

1 Introduction

According to Holzemer *et al.* (2007:541) stigma has been identified as a major confounding problem in the HIV and AIDS pandemic. UNAIDS (2008:8) described the following factors as those that contribute to HIV and AIDS-related stigma: Firstly, HIV and AIDS is considered a life-threatening disease resulting in many people reacting strongly to it. Secondly, HIV infection is linked with behaviours stigmatised in numerous societies, including homosexuality, drug addiction, prostitution or promiscuity. Thirdly, the majority of the people become infected with HIV through sex, which often carries moral baggage. The fourth factor is that there is much incorrect information about how HIV is transmitted, creating irrational behaviour and wrong perceptions of personal risk. HIV infection is often thought to be the effect of personal recklessness (Operario *et al.*, 2010:44). Many religious people believe that persons infected with HIV are the result of promiscuity or 'deviant sex' and that these persons deserve punishment due to their moral fault (UNAIDS, 2008:8).

In the early years of the AIDS epidemic a cycle of influential negative images were used to reinforce and legitimise stigmatisation: Thus, HIV and AIDS was viewed as punishment for immoral behaviour. HIV and AIDS was regarded as horrific and infected people were demonised and feared, resulting in the disease being viewed as a burden to those persons infected. Infected persons were set apart from others (UNAIDS, 2008:8). Herek *et al.* (1999:1106) believe that high stigmatisation of medical conditions is caused by blaming the person for becoming infected. This is due to the fact that the disease is incurable and contagious at present, which may become increasingly more apparent to others.

The stigma of HIV and AIDS has become a major concern, especially because it does not only affect those who are infected, but also those in close relationships with them, such as their spouses or sexual partners, as well as other family members. These

people experience secondary stigma because they are considered to be close to the infected person (Weiss & Ramakrishna, 2001:17). Holzemer *et al.* (2007:547) describe this as associated stigma due to someone living with or working with people living with HIV and AIDS. Thirty years into the pandemic, HIV and AIDS remains one of the most stigmatised medical conditions in the world. Stevelink *et al.* (2011:696) report that persons affected by leprosy are less stigmatised compared to persons living with HIV and AIDS. Stigmatisation that leads to silence, secrecy, and denial does not affect only care and treatment, but it has also serious implications for prevention, which is crucial for preventing a disease with such a long subclinical phase (Greeff *et al.*, 2007:323).

This literature study focuses on the impact of the HIV and AIDS stigma, placing stigma in context, the stigma process, HIV and AIDS stigma reduction interventions for PLHA and their partners, as well as urban and rural differences in HIV stigma experiences.

2 The Impact of HIV and AIDS

It is reported that more than 60 million people have been infected with the virus and about 30 million have died from HIV-related illnesses worldwide since the beginning of the HIV and AIDS epidemic, irrespective of sexual orientation (UNAIDS, 2010:8). UNAIDS (2010:8) estimated that by the end of 2009 there were 33.3 million people living with HIV, as compared to 26.2 million in 1999. The 27% increase meant that sub-Saharan Africa accepted an excessive share of the global HIV burden. The total number of people living with HIV continues to rise, though the rate of new HIV infections has decreased. In 2009, the global total had reached 22.5 million, which is 68%. In the sub-Saharan Africa there are more women living with HIV than men. The countries that used to have the largest epidemics like Ethiopia, Nigeria, South Africa, Zambia and Zimbabwe, have stabilized and are showing signs of decline. In 2009 it was estimated that in sub-Saharan Africa 1.3 million people have died of HIV-related illnesses, which comprises 72% of the global total of 1.8 million deaths attributed to the epidemic (UNAIDS, 2010:25). Southern Africa is still the most severely affected in terms of the pandemic compared to sub-Saharan Africa, which differs significantly. In 2009, 11.3 million people were estimated to be living with HIV in Southern Africa. More than 31% of

the 8.6 million people living with HIV in the past decade. Globally, 34% of people living with HIV in 2009 resided in the 10 countries of Southern Africa. In the same year 31% of new HIV infections and 34% of all AIDS-related deaths were recorded in these 10 countries. There is an approximate 40% adult women living with HIV in Southern Africa (UNAIDS, 2010:28).

According to Siyam'kela (2003:8) and Li *et al.* (2008:432) stigma has a strong impact on individuals, communities and society. It results in a series of excluding behaviours towards people such as isolation, breaking down communities as well as undermining equal human rights. Stigma also causes internalisation of blame and shame, which in turn makes it complicated to fight. It reduces access to HIV prevention, voluntary counselling and testing, treatment and support. Also it makes it difficult for HIV-infected people to access welfare benefits. Stigma and discrimination cause people to be petrified to go for an HIV test. It also allows people to see PLHA as being different and inferior. There is a strong judgmental attitude that makes PLHA feel different. Stigma discourages people from associating with PLHA, lest they are also seen as 'having AIDS' (Duffy, 2005:18).

3 Stigma in Context

The HIV and AIDS pandemic evoked a variety of reactions from individuals and communities. Mann (1987), the founding Director of the World Health Organization's former Global Programme on AIDS, described the AIDS epidemic in any community in three phases. First, the epidemic of HIV infection enters a community silently and often develops over years without being noticed. Second, the epidemic of AIDS itself develops, the syndrome of infectious diseases that is caused by HIV infection, but normally only after a delay of a number of years. The third phase is described as the epidemic of social, cultural, economic and political responses to AIDS. An AIDS activist, Gugu Dhlamini, was stoned and beaten to death by neighbours in her township near Durban, South Africa, after talking openly about her HIV status on World AIDS Day in December 1998 (Brown *et al.*, 2003:51). This is regarded as extremely high levels of stigma, discrimination and denial (Parker & Aggleton, 2003:13).

Holzemer *et al.* (2007:541) believe that silence and denial may be the most invasive reactions to stigma, as signified by the title “Breaking the silence” in the 2000 International AIDS Conference in Durban, South Africa. The highlight of the conference was a look into the potential consequences of AIDS stigma. The conference pointed out the collective communal as well as individuals’ involvement in reducing stigma. Herek *et al.* (2002:372) in their study indicated that between 1991 and 1999, people affected by AIDS and those who are close to them, or social groups to which they belong, have been highly stigmatised worldwide.

3.1 Stigma definition

In Greek the word stigma originated from a type of marking that was cut or burned into the skin of criminals, slaves, or traitors in order to clearly identify them as blemished or morally polluted persons. These individuals were to be avoided or shunned, mostly in public places (Goffman, 1963:11). Goffman (1963:1) refers to this as a dreadful or disgraceful sign by. Nord (1997:11) is also of the same opinion that the mark was a symbol of shame and disgrace, adding that an individual was socially discredited and stigmatised because of that mark.

Goffman (1963:3) provides a seminal theorisation of health-related stigma following his work on criminals and homosexuals in psychiatric hospitals. In his theory he described social stigma as an attribute, behaviour, or reputation that socially discredits an individual and causes that particular person to be mentally classified by others as unwanted and to negatively stereotype them, rather than to accept them in a normal way. He went on to define stigma as a special kind of gap between virtual social identity and actual social identity. A person is reduced in the minds of others from a whole to a tainted and as well as the discounting person. Alonzo and Reynolds (1995:304) also define stigma as a strong discrediting and tainting social label that basically changes the way individuals view themselves and are viewed as persons.

Historically, the term stigma has many associations and implications that are rooted in social science and public health. Weiss and Ramakrishna (2001:1) describe the historical concept of physical stigmata and the sociological framework of deviance and social interactions as that which fall short of research needs to guide desirable public health interventions to decrease stigma. Stigma is described as a social process of an

anticipated outcome and experience characterised by exclusion, rejection and blame. It is also a depression experienced and caused by social judgment about a person or group (Weiss *et al.* 2006:277). Stigma is mainly seen as a trait that discredits or devalues individuals (Brown *et al.*, 2003:49; Link & Phelan, 2001:377). It is progressively deduced as a socially constructed procedure based on the identification by society of certain personal characteristics or attributes as “different” and highly unsolicited (Parker & Aggleton, 2003:17). PLHA are labelled and isolated from the larger community and are regarded as highly unwanted (Holzemer & Uys, 2004:167).

There is a variety of words and phrases used in Southern African communities to name the disease, most of which have negative repercussions (Uys *et al.*, 2005:20). In African languages most given names have a meaning and those meanings are always important. The names given to HIV and AIDS are similar to those used when talking about influential leaders and exceptional personalities – complex, multiple names normally heard in praise poetry and in the reciting of genealogies. Dowling (2005:214) argues that there are two categories for HIV and AIDS that embody the ‘victim’ view, those that view HIV and AIDS as incarnate killer or those named as a taboo in the African languages. There is yet another category that takes its references from popular culture, and virtually almost pokes fun at the pervasiveness of the disease, thus branding it as a game, or a ride on an overloaded train. Examples of this include *UMabulabhuqe* (the indiscriminate killer – Zulu); *UDubul’egeqa* (the one who shoots to kill – Xhosa); *UGawulayo* (the one who chops down – Xhosa); *UQedisizwe* (the finisher of the nation – Zulu) and *UMashayabhuqe* (the beater-up of people – Zulu). There is such a sense of awe surrounding taboos that they may not be named or discussed. This has led to the development of a special language called (*uku*)*hlonipha* (to respect/ to use respectful language). It is made up of substitute words and is a polite and referent language used only for taboos and the ancestral spirits (Pinnock, 1988:61). Stigma is entrenched in these definitions, as one can see from the songs sung in front of persons with HIV and AIDS and the names they are called by community members (Uys *et al.*, 2005:12). The rate of recurrence of such negative labels supports the development of a rationale for devaluing, avoiding, rejecting, and excluding PLHA (Link & Phelan, 2001:385).

3.2 Stigma models

Multiple models exist to explain stigma and HIV and AIDS. Weiss *et al.* (1992:820) describe one of the conceptual models as that which is an insider's (emic) perspective and an outsider's (etic) perspective of the consequences of any illness studied. The emic viewpoint is further defined as that which reflects the way people think of their world, themselves, health and health problems and is embedded in local cultural concepts. The etic viewpoint relates more to professionally defined consequences, for example quality of health and quality of life.

Link and Phelan (2001:363) offer a conceptualization that explains both the socio-cognitive and the structural characteristics of stigma and the relationship between them. Stigma exists when the following four interrelated components congregate: Firstly, individuals discriminate and label human differences. Secondly, there are dominant cultural beliefs that link labelled persons to adverse characteristics (or negative stereotypes). Thirdly, stigma is when labelled persons are placed in a distinct group to achieve some degree of separation between "us" and "them". Fourthly, stigma is also believed to occur when labelled persons experience status loss and discrimination that lead to imbalanced outcomes. Stigmatisation fully depends on inequities in social, economic, and political power that facilitate the unfolding of the four above-mentioned components. Link and Phelan (2001:363) further state that stigma comprises three mechanisms. The first is direct discrimination on a person-to-person level, where actions undervalue, reject, exclude or blame the other person. A second is structural discrimination in social contexts, such as a sign identifying an HIV and AIDS clinic, impose stigma without person-to-person actions. The third mechanism is self-stigmatisation. This is a socio-psychological process that operates through the stigmatised person. According to this mechanism stigmatised persons labels themselves, believe and live according to these labels. Following this model the term labelling, stereotyping and discrimination are all stigma terms used within a power situation that facilitates stigma (Link & Phelan, 2001:364).

The Siyam'kela project (2003:6) classified external and internal indicators for HIV stigma and describes stigma as a complex process that builds up over time and moves between personal and group perceptions, where each feeds off the other. Holzemer *et*

al. (2007:541) developed a conceptual model defining the context and processes of HIV and AIDS stigma. This is developed as conveyed by persons living with HIV and AIDS, as well as nurses from African countries. The stigma process is perceived to emerge within three contextual factors: the environment, healthcare system and the agent. *Environmental* factors consist of culture, economy, politics, legislation and policy. *The healthcare system* includes settings such as hospitals, clinics and home-based care settings and healthcare workers that comprise physicians, nurses and others. *The Agent* includes the individual who may self-stigmatise, family members, work colleagues and community members (Holzemer *et al.*, 2007:541).

Holzemer *et al.* (2007:546) believe that the stigma process takes place within the above-mentioned contexts and includes four elements. These elements are stigma triggers, stigma behaviours, types of stigma and stigma outcomes. The latter conceptual model forms the theoretical grounding of this research.

4 The Stigma Process

Stigma is a complicated process that builds up over time and moves between personal and group perceptions, where each feeds off the other (Siyam'kela, 2003:7). Holzemer *et al.* (2007:547) describe the four elements involved in the stigma process as: triggers of stigma, stigmatizing behaviours, types of stigma and stigma outcomes. These elements are used as a structure to discuss other authors' views.

4.1 Triggers of stigma

Holzemer *et al.* (2007:547) describes a trigger as that which includes an element of 'a marker of difference' and an act that permits people to label themselves or others as HIV positive. The stigma process can be triggered or activated by various factors, such as HIV testing, HIV diagnosis, HIV disease or disclosure of HIV status and suspicion (Holzemer *et al.*, 2007:547). Holzemer *et al.* (2007:547) also believe that disclosure can trigger received stigma. There are three types of stigma namely associated stigma, internal stigma and received stigma (Holzemer *et al.*, 2007:547). Associated stigma can be elicited by constant association with a person(s) who is either suspected of being

HIV positive, is considered as having AIDS, or is certainly infected. Internal stigma can be sparked by persons suspected of being infected confirming their diagnosis when going for testing and receiving an HIV-positive diagnosis. Received and associated stigma is also activated by the dualism (fact or suspicion). Uys *et al.* (2005:20) note that the majority of persons living with and affected by HIV and AIDS reported that even being suspecting of being HIV positive is enough to trigger stigma. These suspicions can be generated through behaviours displayed by the person, such as visiting a specific clinic or displaying a specific symptom such as weight loss. Such suspicions can lead to stigmatising behaviour that Holzemer *et al.* (2007:547) described as 'pestering', continual questioning of the person infected with HIV and AIDS about their diagnosis or behaviour. Due to these stigmatising behaviours PLHA tend to protect their ego by avoiding stigma triggers if at all possible (Holzemer *et al.*, 2007:547).

4.2 Stigmatising behaviour

According to Brown *et al.* (2003:62) triggers leading to stigmatising behaviours are experienced as negative identifiers that can harm, isolate, and/or exclude the person. Holzemer *et al.* (2007:546) in their Conceptual Model identify some of the stigmatising behaviours as blame, insult, avoidance and accusation. The level of stigmatising behaviour may become extremely serious, such as asking a PLHA to use special eating utensils or chasing that particular person out of their home (Holzemer *et al.*, 2007:547). AIDS stigma takes many forms and includes ostracism, rejection, discrimination and avoidance of HIV infected people (Ogden & Nyblade, 2005:3). Researchers further include as stigma compulsory HIV testing without prior consent or protection of confidentiality. Stigma also includes violence against HIV infected individuals or people who are perceived to be infected with HIV and the quarantine of HIV infected persons.

4.3 Stigma types

Literature discusses numerous types of stigma associated with HIV and AIDS. Received, internal and associated stigmas are three types of stigma described by Holzemer *et al.* (2007:547) in their conceptual model. *Received stigma* refers to all types of stigmatizing behaviour towards a person living with HIV and AIDS, as experienced or described by themselves or others. Greeff *et al.* (2008:92) explain the dimensions of received stigma as neglect, fearing contamination, avoidance, rejection,

labelling, pestering, negating, abusing and gossiping. This is parallel to the concept of the etic view of the world, where others direct stigma-related to remarks or actions to the person living with HIV and AIDS (Weiss, 1993:1273). Siyam'kela (2003:14) classifies stigma indicators in two ways, namely external and internal stigma. External stigma includes avoidance, rejection, moral judgment, stigma by association, unwillingness to invest in PLHA, discrimination and abuse. Internal stigma is about self-exclusion from services and opportunities, perception of self, social withdrawal, overcompensation and fear of disclosure. Siyam'kela (2003:5,14-22) goes on to explain that past experience of external stigma influence internal stigma through means of blame, rejection, intimidation, name-calling, exclusion and isolation. Feelings and behaviours following from the person's own negative self-perceptions based on their HIV status is termed internal stigma (Holzemer *et al.*, 2007:547). Dimensions of internal stigma are described by Greeff *et al.* (2008:98) as the perception a person has of him/herself, social withdrawal, self-exclusion and fear of disclosure. This is in line with the emic view of stigma expressed by Weiss (1993:1273) as a person's perceived or self-interpreted view of stigma. Internalised stigma is when PLHA feel that they are to blame, or that they deserve the disease. Stigma of such kind could lead to unwillingness to seek help and to have access resources. PLHA may also fear discrimination and rejection (Siyam'kela, 2003:9).

Associated stigma involves being stigmatised due to a person's association with someone living with, working with or associated by other means to people living with HIV and AIDS (Holzemer *et al.*, 2007:547). Examples may include a family member, or working with a person who is HIV positive (Holzemer *et al.*, 2007:547). This type is also referred to as secondary stigma (Ogden & Nyblade, 2005:31). Manyedi (2007:117) added three classifications that cannot be directly connected to stigma, but are experiences of deterioration in physical status that leads to physical weakness, helplessness, as well as preoccupation with fear of anticipated death. Snyder *et al.*'s (1999:1145) classification is that of three classes of stigma namely instrumental, symbolic and courtesy AIDS stigma. Instrumental AIDS stigma refers to the fear and anxiety that is likely to be associated with any deadly and transmissible illness (Snyder *et al.*, 1999:1145). Symbolic AIDS stigma is linked to the use of HIV and AIDS to express attitudes toward the social groups or lifestyles perceived to be connected with

the diseases (Snyder *et al.*, 1999:1145). Courtesy AIDS stigma refers to stigmatisation of people who are associated with the issue of HIV and AIDS or HIV-positive people (Snyder *et al.*, 1999:1175).

Further categorisations of stigma use the theoretical constructs of perceived, experienced, vivid and felt normative stigma (Sengupta *et al.*, 2010:113). Sengupta *et al.* (2010:113) designed a conceptual model of exploring the relationship between HIV stigma and implementing HIV clinical trials, in which two additional constructs emerged. These constructs are causes of HIV stigma, for example low HIV knowledge and denial in the community, as well as consequences of HIV stigma, for example confidentiality concerns.

4.4 Stigma outcomes

The outcomes of stigma for PLHA were classified into groups of general health, violence, poor quality of life and reduced access to care (Holzemer *et al.*, 2007:550). With reference to poor health resulting from stigma, this refers not only to physical health, but incorporates mental health as well. Mental illness may result from stress aggravated by social exclusion, rejection, high stress due to stigma and economic pressures. Holzemer *et al.* (2007:547) state that AIDS stigma continues to affect people living with and affected by the HIV disease and their health care providers, predominantly in regions where HIV and AIDS is widely spread and prevalent, like Southern Africa. Stigma is perceived as the main obstacle to HIV and AIDS care, as well as to primary and secondary prevention (Greeff *et al.*, 2007:312,323). The experience of stigma is throbbing and causes a great challenge to PLHA, spouses, children and other family members who are often stigmatised through association with them. Kruger *et al.* (2009:28) in their study on the behaviour of newly diagnosed HIV infected people from rural and urban communities found that there are three main aspects that influence health care behaviour. These behaviours come in various forms of stigmatisation, such as aspects around the illness itself, poverty and other factors that influence access to health care services. Stigma-related violence averts the majority of the people from seeking HIV testing, going back for their results or securing treatment. This can perpetuate the spread of HIV and AIDS or possibly develop chronic illness that may lead to death (Kruger *et al.*, 2009:28). There are dynamics involved in

stigmatisation that are usually diverse and complex. These dynamics are HIV-stigma related and contributes to delays and/or absence of diagnostic testing, lack of timely access to health care, and hesitance to disclose information to partners, family, friends and/or employers (Klein *et al.*, 2002:53).

In sub-Saharan Africa where HIV and AIDS are predominant, stigma affects both the infected and the affected, and seems a major concern in most countries. Stigma seems to be intensified by fear attributed to the misconceptions regarding its mode of transmission, its debilitating nature, as well as the high rate of death (Nord, 1997:60). Varas-Diaz *et al.* (2005:169) found that stigma further led to loss of social support, persecution, isolation, job loss, as well as accessing healthcare services of PLHA. A relatively high number of individuals had not disclosed their HIV status to their sexual partners due to fear of stigma and their partners' reactions (Nachega *et al.*, 2005:200). Stigma may affect the behaviour of those who are stigmatised, such as stereotyped persons who often start to perform in ways that their stigmatisers expect of them. These performances do not only include changes in their behaviour, but also shape their emotions and beliefs, leading to low self-esteem (Major & O'Brien, 2005:420).

According to Simbayi *et al.* (2007:29) in South Africa, PLHA who have experienced stigma or discrimination were less likely to disclose their HIV status to their sexual partner and the non-disclosure is connected with transmission risk behaviour. Li *et al.* (2008:435) state that HIV and AIDS stigma impact goes beyond individuals' experiences, as it affects the whole family, the family's identity and interactions. Li *et al.* (2008:435-438) also express that stigma associated with HIV and AIDS has an extensive impact on family identity, relations within the family and broader social networks, and behaviour related to coping is reduced. Fear of contamination attached to negative assumptions about people who are infected leads to high levels of stigma surrounding HIV and AIDS (UNAIDS, 2008:30). Greeff *et al.* (2010:476) reveal that HIV stigma is perceived to have a significant negative and continuous impact on the life satisfaction and quality of life of people living with HIV globally.

Closely linked to the experience of stigma is the experience of discrimination, which always follows stigma (Link & Phelan, 2002:4). Link and Phelan (2001:363) describe discrimination as that which focuses on the individual and social producers of

stigmatisation rather than the recipients of stigma. Discrimination is a result of stigma and is defined when there is an absence of objective justification. A distinction is made against a person that causes him/her to be treated unfairly and unjustly on the basis of belonging or being perceived to belong to a particular group”(Castro & Farmer, 2005:53). Kohi *et al.* (2006:404) purport that stigma and discrimination linked with HIV and AIDS are common in every country and region worldwide. In the sub-Saharan Africa, where AIDS is so significant, stigma and discrimination have a large influence on people living with HIV infection (Dlamini *et al.*, 2007:389; Phaladze *et al.*, 2005:125). People living with HIV fear the social discrimination that might follow after they have disclosed their status. Stigma and discrimination carry on to affect those living with and affected by the HIV disease, particularly in South Africa (Greeff *et al.*, 2010:476; Holzemer *et al.*, 2009:166; Uys *et al.*, 2005:20).

5 HIV and AIDS Stigma Reduction Interventions

Stigma and discrimination have been broadly researched, mainly within the context of health (Sengupta *et al.*, 2010:119). In the context of HIV and AIDS, studies reflected that stigma has several impacts on prevention, treatment access and on care programmes (Brown *et al.*, 2003:62). Therefore, reducing stigma is an essential goal in HIV and AIDS programmes (UNAIDS, 2010:83). However, there is a limited number of published studies on the interventions and programmes designed to reduce HIV and AIDS stigma (Heijnders & van der Meij, 2006:361).

Mann, according to UNAIDS, (2000:6) was one of the first activists for HIV and AIDS-related stigma research on the international stage. He argued that stigma aggravated the effects of the epidemic and decreased the effectiveness of AIDS programming efforts. This increased the amount of research on HIV and AIDS-related stigma internationally in the 1990's and 2000's. Parker and Aggleton (2003:19) state that stigma and discrimination lessen the impact of prevention programmes and impedes treatment take-up and adherence. They further describe stigma and discrimination as that which worsens the psycho-social effects of HIV-infection and reduces the quality of life of people living with HIV and AIDS.

The Siyam'kela project (2003:12) recommends that dealing with stigma needs to take place on many levels, namely a personal level, community and civil society and an institutional level. The personal level is information and education, self-awareness and consciousness-raising. The community and civil society refers to community outreach, awareness campaigns and education. The institutional level is faith-based organisations, the media, workplaces, schools, educational and health institutions. The above-mentioned levels need to be supported by programmes, policies, guidelines and legal frameworks on both national and international levels. UNAIDS (2010:122) states that 91% of governments address stigma and discrimination as they cut across issues of their national strategies. The National Composite Policy Index (NCPI) reported that programmes to address stigma and discrimination have doubled in less than five years. This improvement shows increased acknowledgement of the importance of working to eradicate stigmatisation and discrimination against people living with HIV. However, these reports refer to the existence of such programmes, but they do not confirm whether efforts were implemented at an adequate scale. The extent to which these programmes make real and sustained improvements to the lives of people living with HIV and other members of key populations at higher risk of exposure is also not clearly confirmed (UNAIDS, 2010:122).

A wider search for research conducted on HIV and AIDS-stigma reduction programmes and interventions, in general, on community-based level, and especially for partners of PLHA, follows in this literature study.

5.1 General interventions

Brown *et al.* (2003:49) published several articles on HIV and AIDS stigma interventions in which stigma reduction behaviour or intervention was measured. Most of the studies aimed to upsurge tolerance of PLHA among the general population. Other studies tested interventions to increase willingness to treat PLHA among health care providers. The studies also tested interventions on the coping strategies in dealing with AIDS stigma among PLHA and to the groups at-risk. Findings of the studies advocate that stigma reduction interventions seem to work, at least on a small scale and for the short term, although many gaps remain, specifically in relation to scale and duration of impact and in terms of gendered impact of stigma reduction interventions. Brown *et al.*

(2003:49) summarize the interventions in these studies in four categories namely, information-based approaches, skills building, counselling approaches and contact with affected groups.

The effect of a brief intervention was targeted to decrease HIV-related stigma among service providers (Wu *et al.*, 2008:513). HIV stigma reduction concepts were carried through participatory small activities, including role-plays, games, group discussions, and testimony by an HIV activist. Even though this brief intervention pilot indicated the potential for reducing HIV stigma and discrimination among service providers, more trials are required to test the effectiveness and long-term outcomes of this intervention (Wu *et al.*, 2008:513).

Uys *et al.* (2009:1059) explored HIV-stigma interventions in five African health care settings. The results revealed that stigma reduction intervention involve both information giving and empowerment. This led to a mutual understanding and support between nurses and PLHA. It also created some drive in all settings for the continuation of HIV-stigma reduction activity. The study results conveyed that there was an increase in nurses going for testing, and PLHA who were involved in the intervention teams reported less stigma and increased self-esteem (Uys *et al.*, 2009:1059).

Sengupta *et al.* (2010:119) conducted a systematic review of 19 studies to determine the effectiveness of HIV-related interventions in reducing HIV and AIDS stigma. From 19 studies reviewed, 14 verified the effectiveness in reducing HIV and AIDS stigma. Only two of all the reviewed studies were given general good quality ratings. According to the project by KANCO (2007:1), several interventions and programmes emerged from intensive research projects done in South Africa and Africa as a whole. These interventions included testing on practitioners' ideas, approaches and tools used in different contexts to ensure effectiveness in reducing HIV-related stigma. Quite a number of the interventions directly address HIV-related stigma. Some were designed to empower people living with HIV to overcome stigma and to take action against stigma and discrimination (Heijnders & van der Meij, 2006:361). The National Department of Health, USAIDS Policy Project and UNDP also developed intervention programmes that can assist PLHA (South Africa Department of Health, 2003:1). These interventions are essentially part of a broader campaign intended to respond to the challenges faced by

PLHA in addressing HIV and AIDS at home, in work places and in the communities. The campaign aimed to empower and strengthen PLHA and to decrease the impact of HIV and AIDS stigma. Lessons from the Africa Regional Stigma Training Programme was developed by the International HIV and AIDS Alliance with the aim of integrating stigma reduction into HIV programmes (International HIV/AIDS Alliance, 2011:3). The lessons intended to present different examples of stigma reduction activities that have been integrated into HIV programmes in order to have long-term impact on the sustainability and understanding of the of HIV-stigma challenges. HIV trainers in Africa developed the toolkit for action (Kidd *et al.*, 2003:1). The toolkit was designed to assist trainers to plan and organise groups, to raise awareness and to promote practical action in challenging HIV stigma and discrimination.

The interventions predominantly aim to share information on HIV and AIDS and to increase the understanding of HIV stigma. It also aims to advocate human rights related to gender and violence in the workplace, disclosure, and dealing with HIV stigma, relationships and communication with others. This is to strengthen the position and coping mechanisms of the PLHA in response to stigma. The majority of the programmes involve sharing information and encouraging reinforcement of specific skills in areas mentioned above (Greeff, 2009:2).

5.2 Community-based interventions

There are four models that characterize earlier attempts to scale up community based intervention projects as described by Taylor (2001:11). The first model is the blueprint approach that involves experts choosing successful interventions from local or international experience. The second model is the explosion approach in which only interventions that are focused on national or global priorities are selected. Focused interventions ensure tight control, efficiency and well-resourced vertical hierarchy, which usually duplicate existing management systems. The third model is the additive approach. This is inspired by Non-Governmental Organizations (NGO's) and is also financed by them, with the hope that the intervention would be transferred over to local control. The approach focuses on bottom-up and culturally adapted development based on the pace of the community. The fourth model is the biological approach. This approach begins by identifying active successful community-based projects that exhibit

self-reliant empowerment. According to Chopra and Ford (2005:384) every community is inspired to become a growth node for quick expansion.

According to the Siyam'kela project (2003:26) and Kinsman *et al.* (2002:261) successful community-based programmes have some common features, like their needs and the resources of the community start very small and begin to grow slowly as they change. The whole community is involved in every part of the work, from planning to evaluation. All members of the community are encouraged to participate in the work and to use leaders who are of interest in serving the community. The people running the programmes adapt to the changing needs of those served by the project and remain open to new ideas. In spite of just thinking about health in terms of the prevention and treatment of the disease, people involved in the intervention programmes also include advocacy and lobbying, using policy and legal frameworks. This is done to promote human rights literacy, raising awareness through running workshops and to provide credible information to target influential institutions.

“The fight against stigma: An overview of stigma-reduction strategies and interventions” done by Heijnders and van der Meij (2006:358) intended to add knowledge at community level concerning specific health conditions with regard to stigma within specific community groups. Stigma reduction strategies also aspire to provide better access to services for people affected by increasing community development skills, as well as to develop support networks.

HIV and AIDS stigma was explored in the socio-cultural context of North-Eastern region of Thailand in Nakhon Ratchasima Province (Apinundecha *et al.*, 2007:1157). A community participation intervention was developed through action research. The results from action research propose that community interventions that empower the community together with a financial contribution that lessen resource constraints are of great importance in increasing interaction between people living with HIV and AIDS and other community members. Such interventions also increase tolerance and reduce the HIV and AIDS stigma (Apinundecha *et al.*, 2007:1157).

Zeelen *et al.* (2010:382) explored the role of a small-scale project around story-telling as a type of informal education in five health clinics in the rural areas of the Limpopo Province in South Africa. The aim of the project was to start an open dialogue in local

communities about the disease as a way of enabling reduction of stigma around HIV and AIDS. The research findings emphasized the importance of involving a storyteller with little or no education, but who can play an influential role in local rural communities to pass useful messages about the disease to break the stigma attached to HIV and AIDS.

Entertainment education is also believed to be another communication strategy that can be used to raise awareness and tolerance and to promote action in the battle against HIV and AIDS epidemic and the associated stigma among Africa's men who have sex with men (MSM) (Sallar & Somda, 2011:279). The entertainment education derived from numerous theories can be disseminated through radio or TV. This can convey messages of behaviour and social change by giving the audience an opportunity of social learning through media. Sallar and Somda (2011:304) found that entertainment education could assist in creating awareness and reducing stigma towards MSM, as well as prevent HIV and AIDS contamination. Entertainment education has also huge potential in developing efficient interventions. However, the intervention message has to be culturally adjusted in order to allow better results in the community where entertainment education is used as a communication strategy.

5.3 Interventions with partners of PLHA

The International center for research on women (Duvvury *et al.*, 2006:7-8) guide for community-based organizations aim was to assist a community's effect on behavioural and attitudinal changes that would decrease the spread of HIV and AIDS among mobile and mobility-affected populations. The origins and manifestations of stigma and intimate partner violence, including sexual violence experienced by mobile and mobility-affected sex workers, truckers' helpers and truckers' spouses were the concepts explored and described in the HIV and AIDS stigma and violence reduction intervention project. Interventions that were proposed from the project included cultural shows, advocacy meetings, networking of service providers, and a series of workshops on reflection and change.

Manyedi *et al.* (2010:39) developed a programme to empower women whose partners died of AIDS to cope with stigma. The study focused on programme development, implementation and evaluation during eight sessions. The programme included

orientation, HIV and AIDS and voluntary confidential counselling and testing knowledge, stigma manifestations and effects, coping awareness, coping with internal stigma, dealing with disclosure, coping with received and associated stigma and evaluation of the participants' internalisation of the programme. The findings of the programme reflected positive outcomes for these women as they grew from being lonely, reserved, having negative self-perceptions to being open about their HIV status and being able to share their problems related to stigma. These women were also able to seek support, as well as being selfless by offering assistance to other women in the same situation. They established a home-based care service where they could assist in caring for others (Manyedi *et al.*, 2010:48).

Anticipations of HIV and AIDS stigma can block pregnant women from accepting HIV testing. Therefore interventions that address pregnant women's fears of HIV and AIDS stigma and violence from male partners need to be developed (Turan *et al.*, 2011:1111). Turan *et al.* (2011:1117) continue to state that anticipated HIV and AIDS stigma from the male partner and lack of knowledge of the partner's HIV status are the key factors that cause refusal of HIV testing. Male partners often have the biggest direct impact on the women's life as fears about negative reactions from their close partners could be most predictive (Turan *et al.*, 2011:1118).

Anglewicz and Chintsanya (2011:998) identify reasons for not sharing one's HIV status with a spouse. In their study they found that non-disclosure is gender-based. Thus women who perceive greater HIV and AIDS stigma are less likely to disclose their HIV status to a spouse. On the other hand, men who are worried about HIV infection from extramarital partners are less likely to disclose their HIV status to a spouse.

Some studies have examined stigma and disclosure of PLHA. Suggestions are made for stigma reduction intervention of PLHA and their partners, but few studies could be found that focus on HIV stigma reduction with partners on a community-based level.

6 Urban and Rural Differences in HIV Stigma Experiences

Connolly *et al.* in Greeff *et al.* (2007:312) believe that the impact of the epidemic on all sectors of society will exacerbate as more people progress from asymptomatic HIV to AIDS and this is already visible in urban industries, as well as in the rural villages. Naidoo *et al.* (2007:17) explored the differences between reported existing incidents of HIV stigma in urban and rural communities from five African countries. The findings revealed that urban groups described more incidents of stigmatisation and discrimination than the rural groups. However, Bunn *et al.* (2008:285) in his study done in the United States revealed that HIV and AIDS frequency is escalating in rural areas and PLHA in rural communities reported higher levels of perceived stigma than their urban counterparts. The results also showed that community size was not related to motivation to control prejudice, although there was a significant interaction between community size and community residents' perceptions about the extent to which people in their communities know who they are. There are quite a number of studies on life circumstances of people living with HIV and AIDS that focus on large metropolitan areas (Heckman *et al.*, 2008:138). These studies mostly compared the psychosocial profiles of rural and urban people living with the HIV disease. The findings reflected that people with HIV in rural areas reported a significantly lower life satisfaction, lower perception of social support from family members and friends. They also have the challenge of less access to medical and mental health care, elevated levels of loneliness, and more community stigma compared to their urban counterparts (Heckman *et al.*, 2008:138). From the literature it is clear that there is no consistency regarding whether urban or rural communities experience the most HIV stigma.

7 Conclusion

In the HIV and AIDS pandemic, stigma has been acknowledged as a major confounding problem. Stigma does not only affect the lives of people living with HIV and AIDS, but also the lives of the people living close to them. Authors differ on how they define stigma. Multiple models exist to explain stigma and HIV and AIDS. Closely linked to the experience of stigma is the experience of discrimination, which always follows stigma. Several interventions for stigma reduction aim to increase tolerance and acceptance of

PLHA. The programmes involve the sharing of information, strengthening specific skills, counselling approaches, resource provision and empowering coping. Few studies could be found that focus on HIV-stigma reduction with partners on a community-based level. In the next section the research and findings are presented in an article format.

8 References

- Alonzo, A. & Reynolds, N. 1995. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social science & medicine*, 41(3):303-315.
- Anglewicz, P. & Chintsanya, J. 2011. Disclosure of HIV status between spouses in rural Malawi. *AIDS care: psychological and socio-medical aspects of AIDS/HIV*, 23(8): 998-1005. doi: 10.1080/09540121.2010.542130
- Apinundecha, C., Laohasiriwong, W., Cameron, M.P. & Lim, S. 2007. A community participation intervention to reduce HIV/AIDS stigma, Nakhon Ratchasima province, northeast Thailand. *AIDS care: psychological and socio-medical aspects of AIDS/HIV*, 19(9):1157-1165. doi: 10.1080/09540120701335204
- Brown, L., Macintyre, K. & Trujillo, L. 2003. Interventions to reduce HIV and AIDS stigma: What have we learned? *AIDS education and prevention*, 15(1):49-69. doi: 10.1521/aeap.15.1.49.23844
- Bunn, J.Y., Solomon, S.E., Varni, M.A., Miller, C.T., Forehand, R.L. & Ashikaga, T. 2008. Urban-Rural differences in motivation to control prejudice toward people with HIV/AIDS: The impact of perceived identifiability in the community. *The journal of rural health*, 24(3):285-291. doi: 10.1111/j.1748-0361.2008.00170.x
- Castro, A. & Farmer, P. 2005. Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American journal of public health*, (95):53-59. doi: 10.2105/AJPH.2003.028563
- Chopra, M. & Ford, N. 2005. Scaling up health promotion interventions in the era of HIV/AIDS: challenges for a rights based approach. *Health promotion international*, 20(4): 383-390. doi:10.1093/heapro/dai018
- Dlamini, P.S., Kohi, T.W., Uys, L.R., Phetlhu, R.D., Chirwa, M.L., Naidoo, J.R., Holzemer, W.L., Greeff, M. & Makoe, L.N. 2007. Verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma in five African countries. *Public health nursing*, 24(5):389-399. doi: 10.1111/j.1525-1446.2007.00649.x
- Dowling, T. 2005. As sweet by another name. *South African medical journal*, 95(4):214-216.

Duffy, L. 2005. Suffering, shame, and silence: The stigma of HIV/AIDS. *Journal of the association of nurses in AIDS care*, 16(1):13-20. doi:10.1016/j.jana.2004.11.002

Duvvury, N., Prasad, N. & Kishore, N. 2006. HIV & AIDS—Stigma and violence reduction intervention manual: International Center for Research on Women (ICRW). Washington DC: ICRW.

Goffman, E. 1963. Stigma: Notes on the management of spoiled identity. Englewood Cliffs, N.J.: Prentice-Hall.

Greeff, M. 2009. A comprehensive community-based HIV stigma reduction and wellness enhancement intervention. (SANPAD research proposal, 15 September 2009. Reference number 09/15). (Unpublished).

Greeff, M., Phetlhu, D.R., Makoe, L.N., Dlamini, P.S., Holzemer, W., Naidoo, J., Kohi, T.W., Uys, L. & Chirwa, M.L. 2007. Disclosure of HIV/AIDS status: Experiences and perceptions of persons living with HIV/AIDS and nurses in five African Countries. *Qualitative health research*, 18(3):311-324. doi: 10.1177/1049732307311118

Greeff, M., Uys, L.R., Holzemer, W.L., Makoe, L.N., Dlamini, P.S., Kohi, T.W., Chirwa, M.L., Naidoo, J.R. & Phetlhu, D.R. 2008. Experience of HIV/AIDS stigma of PLWA and nurses involved in their care from five African Countries. *African journal of nursing and midwifery*, 10(1): 78-108.

Greeff, M., Uys, L.R., Wantland, D., Makoe, L., Chirwa, M., Dlamini, P., Kohi, T.W., Mullan, J., Naidoo, J.R., Cuca, Y. & Holzemer, W.L. 2010. Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: A longitudinal study. *International journal of nursing studies*, 47:475-486. doi:10.1016/j.ijnurstu.2009.09.008

Heckman, T.G., Somlai, A.M., Kalichman, S.C., Franzoi, S.L. & Kelly, J.A. 2008. Psychosocial differences between urban and rural people living with HIV/AIDS. *The journal of rural health*, 14(2):138-145. doi: 10.1111/j.1748-0361.1998.tb00615.x

Heijnders, M. & van der Meij, S. 2006. The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, health & medicine*, 11(3):353-363. doi: 10.1080/13548500600595327

Herek, G.M., Capitanio, J.P. & Widaman, K.F. 1999. AIDS stigma and sexual prejudice. *American behavioral scientist*, 42(7):1130-1147. doi: 10.1177/0002764299042007006

Herek, G.M., Capitanio, J.P. & Widaman, K.F. 2002. "HIV-related stigma and knowledge in the United States: prevalence and trends, 1991-1999." *American journal public health*, 92(3):371-377. doi: 10.2105/AJPH.92.3.371

Holzemer, W.L., & Uys, L.R. 2004. Managing AIDS stigma. *Journal of social aspects of HIV/AIDS*, 1(3):311-324.

Holzemer, W.L., Uys, L.R., Makoe, L., Stewart, A., Phetlhu, R., Dlamini, P., Greeff, M., Kohi, T.W., Chirwa, M., Cuca, Y. & Naidoo, J. 2007. A conceptual model of HIV/AIDS

stigma from five African countries. *Journal of advanced nursing*, 58(6):541-551. doi: 10.1111/j.1365-2648.2007.04244.x

Holzemer, W.L., Human, S., Arudo, J., Rosa, M.E., Hamilton, M.J., Corless, I., Robinson, L., Nicholas, P.K., Dean, J., Wantland, S.M., Willard, S., Kirksey, K., Partillo, C., Sefoik, E., Mendez, M.R. & Maryland, M. 2009. Exploring HIV stigma and quality of life for persons living with HIV infection. *Journal of the association of nurses in AIDS care*, 20(3):161-168. doi:10.1016/j.jana.2009.02.002

International HIV/AIDS Alliance. 2011. Integrating stigma reduction into HIV programming: Lessons from the Africa Regional Stigma Training Programme. United Kingdom: .SIDA & NORAD.

Kanco. 2007. Training guide on stigma and discrimination in relation to HIV and AIDS. Kenya AIDS NGO'S consortium (KANCO): Nairobi.

Kidd, R., Clay, S. & Chiya, C. 2003. Understanding and challenging HIV stigma: Toolkit for action. <http://www.icrw.org/files/publications/Understanding-and-Challenging-HIV-Stigma-Toolkit-for-Action.pdf> Date of access: 13 Nov. 2013.

Kinsman, J., Komali, A., Kanyesigye, E., Kamulegeya, I., Basajja, V., Nakiyingi, J., Schenk, K. & Whitworth, J. 2002. Quantitative process evaluation of a community-based HIV/AIDS intervention in rural Uganda. *Health education research*, 17(2):253-265. doi: 10.1093/her/17.2.253

Klein, S.J., Karchner, W.D. & O'Connell, D.A. 2002. Interventions to prevent HIV-related stigma and discrimination: Findings and Recommendations for public health practices. *Journal for public health management and practice*, 8(6):44-53.

Kohi, T.W., Makoe, L., Chirwa, M., Holzemer, W.L., Phetlhu, D.R., Uys, L.R., Naidoo, J., Dlamini, P.S. & Greeff, M. 2006. HIV and AIDS stigma violates human rights in five African Countries. *Nursing ethics*, 13(4):404-415. doi: 10.1191/0969733006ne865oa

Kruger, A., Greeff, M., Watson, M.J., Fourie, C.M.T. 2009. Health care seeking behaviour of newly diagnosed HIV infected people from rural and urban communities in the North West Province of South Africa. *Africa journal of nursing midwifery*, 11(2):28-45.

Li, L., Wu, Z., Wu, S., Manhong, J., Lieber, E. & Lu, Y. 2008. Impacts of HIV/AIDS stigma on family identity and interactions in China. *Families, systems & health*, 26:431-422. doi: 10.1037/1091-7527.26.4.431

Link, B.G. & Phelan, J.C. 2001. Conceptualising stigma. *Annual review of sociology*, 27:363-385.

Link, B.G. & Phelan, J.C. 2002. On stigma and its public health implications. <http://www.stigmaconference.nih.gov/FinalLinkPaper.html> Date of access: 22 August 2010.

Major, B. & O'Brien, L.T. 2005. The social psychology of stigma. *Annual review of psychology*, 56(1):393-421. doi: 10.1146/annurev.psych.56.091103.070137

Mann, J. 1987. Statement at an informal briefing on AIDS to the 42nd session of the United Nations General Assembly. New York.

Manyedi, M.E. 2007. Coping with stigma by women whose partners died of AIDS. Potchefstroom: North-West University (NWU). (Thesis – PhD.).

Manyedi, M.E., Greeff, M. & Koen, M.P. 2010. Implementing a programme for coping with stigma for women whose partners died of AIDS: A case study. *Africa journal of nursing and midwifery*, 12(1):39-51.

Nachega, J.B., Lehman, D.A., Hlatshwayo, D., Mothopeng, R., Chaisson, R.E., & Karstaedt, A.S. 2005. HIV/AIDS and antiretroviral treatment knowledge, attitudes, beliefs and practices in HIV-infected adults in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndromes*, 38(2):196-201.

Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoe, L., Dlamini, P., Phetlhu, R.D., Chirwa, M. & Kohi, T. 2007. Urban and rural differences in HIV/AIDS stigma in five African countries. *African journal of AIDS research*, 6(1):17-23. doi: 10.2989/16085900709490395

Nord, D. 1997. Multiple AIDS-related loss: a handbook for understanding and surviving a perpetual fall. Washington, D.C.: Taylor & Francis.

Ogden, J. & Nyblade, L. 2005. Common at its core: HIV-related stigma across context. Washington DC: International Center for Research on Women (ICRW). <http://www.icrw.org/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf> Date of access: 13 Nov. 2013.

Operario, D., Smith, C.D., Arnold, E. & Kegeles, S. 2010. The Bruthas Project: Evaluation of a community-based HIV prevention intervention for African American men who have sex with men and women. *AIDS education and prevention*, 22(1):37-48. doi: 10.1521/aeap.2010.22.1.37

Parker, R. & Aggleton, P. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine*, 57:13-24. doi: [http://dx.doi.org/10.1016/S0277-9536\(02\)00304-0](http://dx.doi.org/10.1016/S0277-9536(02)00304-0)

Phaladze, N.A., Human, S., Dlamini, S.B., Hulela, E.B., Hadebe, I.M. & Sukati, N.A. 2005. Quality of life and the concept of “living well” with HIV/AIDS in sub-Saharan Africa. *Journal of nursing scholarship*, 37(2), 120-126. doi: 10.1111/j.1547-5069.2005.00023.x

Pinnock, P. 1988. Xhosa - a cultural grammar for beginners. Cape Town: African Sun Press.

Sallar, A.M. & Somda, D.A. 2011. Homosexuality and HIV in Africa: An essay on using entertainment education as a vehicle for stigma reduction. *Sexuality & culture*, 15:279-309. doi: 10.1007/s12119-011-9094-1

Sengupta, S. Strauss, R.P., Miles, M.S., Roman-Isler, M., Banks, B. & Corbie-Smith, G. 2010. A Conceptual model exploring the relationship between HIV stigma and

implementing HIV clinical trials in rural communities of North Carolina. *North Carolina medical journal*, 71(2):113-122.

Siyam'kela. 2003. Siyam'kela measuring HIV/AIDS related stigma: A report on the fieldwork leading to the development HIV/AIDS stigma indicators and guidelines. Policy Project, South Africa: Centre for the Study of AIDS. University of Pretoria; United States Agency for International Development; Chief Directorate: HIV, AIDS, TB, Department of Health. <http://www.csa.za.org> Date of access 13 Nov. 2013.

Simbayi, L.C., Kalichman, S.C., & Strebel, A. 2007. Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. *Sexually transmitted infections*, 83:29–34. doi: 10.1136/sti.2006.019893

Snyder, M., Omoto, A.M. & Crain, A.L. 1999. Punished for their good deeds: stigmatisation for aids volunteers. *American behavioral scientist*, 42(7):1175-1192. doi: 10.1177/0002764299042007009

South Africa. Department of Health. 2003. To the other side of the mountain: The faces and voices of people living with HIV and AIDS in South-Africa. Department of Health: Pretoria.

Stevelling, S.A., van Brakel, W.H. & Augustine, V. 2011. Stigma and social participation in Southern India: Differences and commonalities among persons affected by leprosy and persons living with HIV and AIDS. *Psychology, health & medicine*, 16(6):695-707. doi: 10.1080/13548506.2011.555945

Taylor, C. 2001. Scaling up for Social Development. Sussex: ILEIA. United Nations Development Programme (2000) Human Development Report 2000. New York: UNDP.

Turan, J.M., Bukusi, E.A., Onono, M., Holzemer, W.L., Miller, S. & Cohen, C.R. 2011. HIV/AIDS Stigma and refusal of HIV testing among pregnant women in rural Kenya: Results from the MAMAS study. *AIDS and behavior*, 15:1111-1120. doi: 10.1007/s10461-010-9798-5

UNAIDS. 2000. Report on the Global HIV/AIDS Epidemic. http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/report/2000/2000_gr_en.pdf Date of access: 13 Nov. 2013.

UNAIDS. 2008. Report on the global AIDS epidemic. http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/globalreport/2008/jc1510_2008globalreport_en.pdf Date of access: 13 Nov. 2013.

UNAIDS. 2010. UNAIDS report on the global aids epidemic. http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf Date of access: 13 Nov. 2013.

Uys, L.R., Chirwa, M., Dlamini, P., Greeff, M., Kohi, T., Holzemer, W., Makoae, L., Naidoo, J.R. & Phetlhu, R. 2005. Eating plastic, winning the lotto, joining the WWW: Descriptions of HIV/AIDS in Africa. *Journal of the association of nurses in AIDS care*, 16(3): 11-21. doi:10.1016/j.jana.2005.03.002

- Uys, L., Chirwa, M., Kohi, T., Greeff, M., Naidoo, J., Makoae, L., Dlamini, P., Durrheim, K., Cuca, Y., Holzemer, W.L. 2009. Evaluation of a health setting-based stigma intervention in five African countries. *AIDS patient care and STDs*, 23(12):1059-66. doi:10.1089/apc.2009.0085
- Varas-Diaz, N., Serrano-Garcia, I. & Toro-Alfonso, J. 2005. AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. *Qualitative health research*, 15(2):169-187. doi: 10.1177/1049732304272059
- Weiss, R.A. 1993. "How does HIV cause AIDS?" *Science magazine*, 260(5112):1273-1279. doi: 10.1126/science.8493571
- Weiss, M.G., Doongaji, D.R. & Siddhartha, S. 1992. The Explanatory Model Interview Catalogue (EMIC) contribution to cross-cultural research methods from a study of Leprosy and Mental Health. *British journal of psychiatry*, 160:819-830. doi: 10.1192/bjp.160.6.819
- Weiss, M.G. & Ramakrishna, J. 2001. Conference examines need for more study of AIDS stigma. *AIDS policy law*, 16(18), 4.
- Weiss, M.G., Ramakrishna, J. & Somma, D. 2006. Health-related stigma: rethinking concepts and interventions. *Psychology, health & medicine*, 11(3): 277-287.
- Wu, S., Wu, Z., Ling, L., Coa, H., Yan, Z. & Lil, J. 2008. A brief HIV stigma reduction intervention for service providers in China. *AIDS patient care and STD'S*, 22(6):513-518. doi: 10.1089/apc.2007.0198
- Zeelen, J., Wijbenga, H., Vintges, M. & de Jong, G. 2010. "Beyond silence and rumor: Storytelling as an educational tool to reduce the stigma around HIV/AIDS in South Africa". *Health education*, 110(5):382-398. doi: 10.1108/09654281011068531

SECTION C: ARTICLE

TITLE: A community-based HIV stigma reduction intervention for people living with HIV and their partners

JOURNAL: Africa Journal of Nursing and Midwifery

Guidelines for Africa Journal of Nursing and midwifery

Please adhere strictly to these instructions to facilitate the publication process of articles. Each article submitted must contain:

- The exact appropriate title – use as few words as possible
- The surname and initials of the author/s in the correct sequence
- Highest academic qualification of every author
- The department and institution/university to which the work should be attributed
- Telephone, fax numbers and email address of the corresponding author (to whom galley proofs should be sent)
- Declaration signed by the corresponding author

GENERAL REQUIREMENTS

An abstract not exceeding 250 words should be on a separate page, covering the purpose of the research article, research methodology, major findings and recommendations. This should be followed by 4-6 keywords in alphabetical order. The total length of the article should not exceed **5000 words** from the first word in the title to the last word in the list of references. Avoid/limit the use of abbreviations. The abbreviated Harvard system of referencing should be used in the text. Cite the author's surname, followed by a comma, then the year of publication and page number (Jones, 2007:231). More than one reference per year per author must be distinguished by using alphabetic letters (Jones, 2007a, and 2007b). Preferably no more than 25 references should be included in the list of references; in alphabetic order (according to the surname of the first author). Only System International (SI) units should be used. English spelling should conform to that of the Concise Oxford Dictionary.

Complete and correct titles of books and journals must be supplied and written in italics. For books the city (not the country nor the state) of publication and the name of the publisher must be supplied (Evian, L. 2003. *Primary Aids care*. 2nd Edition. Johannesburg: Jalana). Journals' titles may not be abbreviated.

Tables (maximum of 3) should be single spaced in the correct position in the text (table 1; table 2), with the heading on top of the table. All abbreviations used should be defined in a note immediately below the table.

Figures (maximum of 2) should be presented in the correct places in the text and must be in black and white only, and the title of the figure must be below the figure.

Acknowledgements should be brief and recognise sources of financial and logistical support and permission to reproduce materials from other sources. Enclose a copy of documentation granting such permission. Adherence to copyright rules remains each author's sole responsibility.

All manuscripts must be submitted in MSWORD format via email to ehlervj@unisa.ac.za. No hard copies should be posted.

Referees will only review articles adhering to the author guidelines; their recommendations will be communicated to the corresponding author.

Galley proofs must be returned to the editor within 3 days otherwise the article may be printed in a later edition. Only typographical errors and other essential changes may be made at this stage.

Authorship credit implies that listed authors should meet the criteria contributing to the conception, design, analysis, interpretation of data, drafting and revising the manuscript, and approving the final version. Participation in the acquisition of funding and/or data collection does not merit authorship credit. The corresponding author will normally be the first author.

Publication Fees will be charged at R150.00 (one hundred and fifty Rand) per published page during 2011. An account will be rendered to the corresponding author who will be held responsible for payment.

PLEASE ADHERE TO THE FOLLOWING OUTLINE WHEN WRITING YOUR MANUSCRIPT:

Title: BOLD CAPITALS TYPED IN AERIAL NARROW SIZE 14

Authors' initials, surname, highest qualifications and affiliations typed in Aerial Narrow 11: for example: V.J.

Ehlers, D Litt et Phil, University of South Africa, Department of Health Studies

Abstract typed in Verdana 10 not exceeding 250 words – single spacing. Refer to background, significance of study, research methods used, most important findings and recommendations.

Keywords: 4-6 in alphabetical order typed in Verdana 10

The actual article must be typed in Aerial Narrow 11 using single line spacing, and must include the following sections:

INTRODUCTION AND BACKGROUND INFORMATION: Discuss the importance of the study and include a brief literature review, using only sources published since 2000, preferably since 2005.

STATEMENT OF THE RESEARCH PROBLEM should be done clearly and concisely. The significance of the problem/issue should also be specified.

PURPOSE OF THE STUDY, OBJECTIVES, ASSUMPTIONS, RESEARCH QUESTIONS depending on the nature of the study

DEFINITIONS OF KEYWORDS/CONCEPTS. These must be supplied in alphabetical order and must include every term mentioned under 'keywords'. Please use full sentences with the key term in bold, for example: An adolescent mother is any woman aged 19 or younger who has given birth to an infant, irrespective of the pregnancy outcome and irrespective of her marital status.

RESEARCH METHODOLOGY should address the design, research site, study population and sample and sampling techniques, size of sample. Under the research instrument the development, structure, reliability, validity (or trustworthiness) and the pre-test need to be addressed. The data collection procedure needs to be discussed in sufficient detail and the exact dates of data collection must be specified. Data analysis procedures must be explained.

ETHICAL CONSIDERATIONS must specify how permission was obtained to conduct the study and how participants/respondents were protected from exploitation. Confidentiality and anonymity should be addressed and adhered to. No identification tags should indicate potential respondents' verbatim quotations. Names of hospitals and healthcare institutions should preferably not be used.

ANALYSIS commences with the demographic information of the participants/respondents. Thereafter the results should be presented according to the research questions. In this section ONLY present the current study's findings.

DISCUSSION OF RESEARCH RESULTS Discuss the results in the same sequence as the analysis, compare and contrast the study's findings with those of other studies.

CONCLUSIONS must be based on the research results.

RECOMMENDATIONS follow from the conclusions. Recommendations that are irrelevant to the current study should be avoided.

LIMITATIONS OF THE STUDY must be specified so that the readers can interpret the significance of the findings and recommendations within the context of the limitations.

Acknowledgements: must be brief and to the point.

REFERENCES : these must be typed in single spacing and Verdana 10. Leave one space open between successive references. This list must be in alphabetical order according to the surname of the first author. Abbreviations such as WHO should be used in the text but in the list of references the full name World Health Organization must be written out. In case of Internet references, the date on which the information was accessed should be indicated in brackets. Check every Internet reference, if it is correct and shown in blue, and if one double-clicks on this reference, one should automatically be linked to the document/article/site concerned.

STYLE: no numbers should be used in headings or in lists; avoid using bullets – they take up too much space to print – try to use semi-colons instead. Please use the past tense and plural nouns wherever possible – most authors commit fewer errors this way. Editing of the article is the responsibility of the authors. Articles that require editing will be returned to authors for editing before being sent to reviewers.

TYPES OF ARTICLES PUBLISHED: The AJNM strives to provide worthwhile information to the nurses and midwives of Africa, not necessarily nurse academics. Consequently articles should address healthcare issues faced by nurses and midwives throughout Africa. Empirical research articles are preferred. Articles based on theory only might be inappropriate, as well as articles based on textbooks' information. As the AJNM is an accredited academic journal, it needs to adhere to the minimum requirements of the Department of Higher Education and Training of South Africa. This means that mostly empirical peer reviewed research articles should be published, but a limited number of pages can contain book reviews or reports of conferences. In exceptional cases one article per issue might address research issues per se. The decisions of the reviewers and the editors are final.

No more than two articles will be published about any specific research project in the AJNM. No articles will be published as part 1 and part 2. In every AJNM issue, no person may author more than one sole authored or more than two co-authored articles.

Copyright of an article will be assigned to the AJNM if the article is published. Copyright covers the exclusive right to reproduce and distribute the article in any medium. Articles published by the AJNM, will be available from the institutional repository of the University of South Africa (<http://uir.unisa.ac.za>). Submitting any article to the AJNM, implies that it presents original, unpublished work, and is not considered for publication elsewhere. Without such a declaration no article will be sent to reviewers. The corresponding author needs to sign the following agreement to this effect. It remains the right of the AJNM to submit any article to the "Turn-it-in" computer program to determine its extent of non-original information.

DECLARATION TO BE SIGNED BY THE CORRESPONDING AUTHOR AND SUBMITTED WITH EACH ARTICLE

I, as corresponding author of the article (submitted to the AJNM) entitled, hereby declare that this is an original article which has never been published previously and which is not under consideration for publication by any other journal. The data were collected from to

Signature: Date:

Please specify the specific contributions of each author

Names and e-mail addresses of at least three reviewers considered suitable for reviewing the above article:

(Please note that the editors of the AJNM may or may not refer any article to the recommended reviewers. The editors' decisions remain final in this regard

A COMMUNITY-BASED HIV STIGMA-REDUCTION INTERVENTION FOR PEOPLE LIVING WITH HIV AND THEIR PARTNERS

Authors:

Mrs. M.H. Louwrens, MCur. candidate, North-West University, Potchefstroom Campus

Prof. Dr. M. Greeff, DCur. (RAU), Professor in research, Africa Unit for Transdisciplinary Health Research (AUTHeR). North-West University, Potchefstroom Campus.

Dr. M. E. Manyedi, Ph.D (NWU), Senior Lecturer, Quality Assurance. North-West University, Mafikeng Campus.

Corresponding author:

Prof. Dr. M. Greeff,

AUTHeR, North-West University,

Private Bag X6001,

Potchefstroom, 2520, South Africa

Tel: +27 18 299 2092, Fax: +27 18 299 2088, E-mail: minrie.greeff@nwu.ac.za

Acknowledgements:

SANPAD for the bursary and financial support received to conduct the research. This study is part of a bigger comprehensive community-based HIV-stigma reduction and wellness enhancement intervention study. Mrs. Molaudzi, as research assistant and all the participants.

Abstract

The diagnosis of HIV impacts the lives and the relationships of both people living with HIV or AIDS (PLHA) and their partners. The researchers aimed to describe the effect of a community-based HIV stigma reduction intervention on PLHA and their partners by means of a case study method. In addition, the research aims to explore and describe the lived experiences of these two groups during and after the intervention in both an urban and a rural setting of the North West Province, South Africa. A qualitative holistic multiple case study design and interpretive description approach through in-depth interviews was used to implement and evaluate the intervention. Purposive voluntary sampling was conducted to access PLHA and snowball sampling for their partners. The case record included multiple sources. Document analysis and open coding was used for analysis of case records and open coding for in-depth interviews. No real differences were noted between the urban and rural groups. In both the case study and the expressed experiences it was evident that the intervention was successful. Follow-up interventions with PLHA and partners are suggested.

Keywords: HIV Stigma, Intervention, Partner, Rural, Stigma reduction, Urban.

1 Introduction and Problem Statement

This study was part of a bigger comprehensive community-based HIV stigma reduction intervention study involving children, family, partners, friends, spiritual leaders and community members, as people living close to people living with HIV or AIDS (PLHA). The focus of this study was on the HIV-stigma reduction intervention and the lived experiences during and after the intervention with PLHA and specifically their partners. In this study partner refers to the person that is closely related and associated with PLHA as a spouse or boyfriend/girlfriend, both married or unmarried.

Globally, 34.0 million people were living with HIV at the end of 2011 (UNAIDS, 2012:8). However, sub-Saharan Africa remains the most severely affected, with an estimated 23.5 million people living with HIV (UNAIDS, 2012:14). During 2001 to 2011 South-Africa showed a decrease in the rate of infections among adults (UNAIDS, 2012:11), yet an estimated 316 900 adult South-Africans were newly infected during 2011 (Statistics SA, 2011:12). HIV treatment has allowed PLHA to live longer, reducing AIDS to a chronic condition, but increasing the opportunity for the unwanted disclosure of the illness to others. This forced PLHA to confront stigma and isolation in their workplace and community (Apinundecha *et al.*, 2007:1157). Greeff *et al.* (2010:476) mention that AIDS stigma continues to affect people living with and affected by the HIV disease, as well as their health care providers, particularly in regions where HIV and AIDS are widespread, such as in South Africa. Stigma has emerged as a major barrier to HIV and AIDS care, as well as to primary and secondary prevention. Varaz-Diaz *et al.* (2005:169) found that stigma led to a loss of social support, persecution, isolation, job loss and the already mentioned problem of accessing healthcare services. The experience of stigma is painful and difficult for PLHA and for their spouses, children and family who are often stigmatised through their association with PLHA (Greeff & Phetlhu, 2007:23).

Stigma has over time been defined by various authors, but is mainly seen as an attribute that discredits or devalues individuals who possess it (Brown *et al.*, 2003:49). Alonzo and Reynolds (1995:304) followed on Goffman's (1963:3) definition by defining stigma as a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons. It is increasingly interpreted as

a socially constructed process based on society's identification of certain personal characteristics or attributes as "different" and highly undesirable (Parker & Aggleton, 2003:17; Siyam'kela, 2003:13). As an HIV- positive status is seen as highly undesirable, PLHA are labelled and set apart from the larger community (Holzemer & Uys, 2004:167). HIV and AIDS stigma is a socio-economic-psychological phenomenon that affects not only PLHA, but also their family and the community (Apinundecha *et al.*, 2007:1157). Partners can often have the biggest direct impact on the life of the other partner and thus it is not surprising that fears about negative reactions of stigmatisation from these close persons would be most predictive (Turan *et al.*, 2011:1118). However, being a partner living close to a PLHA may also subject a person to associated stigma (Greeff *et al.*, 2008:107).

The impact of the epidemic on all sectors of society, from urban industries to rural villages, is already being felt and will worsen as more people progress from asymptomatic HIV to AIDS (Connolly *et al.*, 2004:776) in Greeff *et al.* (2007:312). Authors differ as to whether stigma is highest in urban or in rural settings. Naidoo *et al.* (2007:23) found that urban groups described more incidents of stigmatisation and discrimination than did the rural groups. It might be argued that urban discussion groups express themselves more fluently and are more confident with researchers: however, the groups in rural areas were as keen to discuss their experiences and seemed as forthcoming in describing incidents. The findings by Bunn *et al.* (2008:285) contradict the results of Naidoo *et al.* (2007:23). Bunn *et al.* (2008:285) found that the HIV-related stigma was relatively more frequent in rural areas. Heckman *et al.* (2008:138) found that rural people reported a significantly lower satisfaction with life, social support from family members and friends, reduced access to medical and mental health care, elevated levels of loneliness, and more community stigma. From the literature it is clear that there is no consistency regarding whether urban or rural communities experience the most HIV stigma.

Several HIV stigma reduction programmes, workshops and interventions have been implemented. The interventions mostly aim to share information on HIV and AIDS, increasing an understanding of HIV stigma, human rights, advocacy, gender, violence, the workplace, disclosure, dealing with HIV stigma, relationships and communication with others, strengthening the position or coping of the PLHA, as well as how health

care professionals should respond to stigma (Greeff, 2009:2). Brown *et al.* (2003:49) evaluated a variety of interventions to decrease AIDS stigma in developed and developing countries. They summarized the interventions in these studies to be one of four types, namely: information-based approaches; skills building; counselling approaches and contact with the affected group (Brown *et al.*, 2003:49). Results suggest some stigma reduction interventions appear to work, at least on a small scale and in the short term, but this is inadequate, especially in relation to scale and duration of impact of stigma reduction intervention (Greeff, 2009:3). Uys *et al.* (2009:1060), targeting health care settings, support findings by Brown *et al.* (2003:52-53), but added extra categories: increasing contact with the affected group, increasing knowledge of stigma and improving coping through empowerment, leaving out the skills building component. They found that the intervention increased understanding and knowledge of HIV stigma and discrimination, enhanced relationships and there was a significant increase in voluntary testing by nurses (Uys *et al.*, 2009:1064).

Although some studies have examined stigma and disclosure of PLHA, there are not many studies concerning interventions for stigma reduction and wellness enhancement for PLHA and their partners. Manyedi (2007:3) examined the coping strategies that women whose partners died of AIDS employed to overcome stigma and developed a programme to empower women whose partners died of AIDS to cope with stigma (Manyedi *et al.*, 2010:39). Valerian *et al.* (2002:415) studied the impact of perceived HIV-related stigma on the relationship after the HIV positive party finds out about the sero-positive diagnosis and discloses it to the partner. Heijnders and van der Meij (2006:361) mention that many interventions and programmes emerged from intensive research projects in South Africa and Africa. Some of the interventions directly address HIV-related stigma and others were designed to empower people living with HIV to overcome stigma and to act against stigma and discrimination (Siyam'kela, 2003:12; Sallar & Somda, 2011:279; Taylor 2001:1; Wu *et al.*, 2008:513; Zeelen *et al.*, 2010:382). Only a small number of these studies have been published (Sengupta *et al.*, 2010:119).

From the discussion it is clear that the positive diagnosis of HIV impacts the lives and the relationships of both PLHA and their partners. This could be a result of the PLHA being stigmatised by the partner, as well as associated stigmatisation experienced by the partner due to being linked with the PLHA. The literature review makes it obvious

that a limited amount of research has been performed on interventions to reduce HIV stigma in PLHA and their partners and this matter subsequently forms the focus of this study. Based on the stated problem, the following questions arose: In what way can a community-based HIV stigma reduction intervention reduce stigma in PLHA and their partners in an urban and a rural setting in the North West Province; and what are the experiences of PLHA and their partners during and after of a community-based HIV stigma reduction in an urban or a rural setting in the North West Province?

2 Objectives

The research aimed to describe the effect of a community-based HIV stigma reduction intervention on PHLA and their partners by means of a case study method. The article also endeavours to explore and describe the lived experiences of these two groups during and after the intervention in both an urban and a rural setting of the North West Province, South Africa.

3 Literature Review

Sub-Saharan Africa still bears an inordinate share of the global HIV burden of the people living with HIV worldwide (UNAIDS, 2012:8). What is more, HIV remains one of the most stigmatised medical conditions in the world. Thus stigmatisation resulting in silence, secrecy, and denial not only affects care and treatment, but it also has serious implications for prevention, which is critical in a disease with such a long subclinical phase. Stigma may be the most pervasive reaction (Greeff *et al.*, 2007:323; Holzemer *et al.*, 2007:541).

Stigma has a powerful impact on individuals, communities and society. It results in a range of excluding behaviours towards people such as isolation, division and breaking down communities and, undermining equal human rights (Siyam’kela, 2003:8; Li *et al.*, 2008:434). This highlights the potential consequences of AIDS stigma and points to the collective and communal, as well as the individual level of involvement needed to

reduce stigma (Siyam'kela, 2003:8). Male partners often have the biggest direct impact on women's lives and thus it is not surprising that fears about negative reactions from these influential close persons are most predictive (Turan *et al.*, 2011:1118). Anglewicz and Chintsanya (2011:998) identify that both men and women sometimes keep their HIV status completely secret. Obermeyer *et al.* (2011:1), however, found that few people keep their status completely secret.

Several conceptual frameworks for understanding HIV stigma have been proposed. Link and Phelan (2001:363) offer a conceptualization that elucidates both the socio-cognitive and the structural aspects of stigma and the relationship between them. The Siyam'kela (2003:6) project aimed at developing indicators for HIV stigma. Holzemer *et al.* (2007:541) developed a conceptual model of HIV and AIDS stigma, delineating the context and the process of HIV and AIDS stigma. The stigma process is conceived to occur within three contextual factors: the environment, the healthcare system and the agent. The stigma process takes place within these three mentioned contexts and is proposed to include four elements: stigma triggers, stigma behaviours, types of stigma and stigma outcomes (Holzemer *et al.*, 2007:546). This model forms the theoretical framework for this research.

The three types of stigma mentioned by Holzemer *et al.* (2007:547) are received, internal and associated stigma. Other authors use different terms. *Received stigma* refers to all types of stigmatizing behaviour, such as avoidance and rejection towards a PLHA, as experienced or described by themselves or others (Holzemer *et al.*, 2007:547). It is similar to the concept of the etic view (Weiss, 1993:1273) and external stigma (Siyam'kela, 2003:14). *Internal stigma* according to Holzemer *et al.* (2007:547) includes thoughts and behaviours stemming from the person's own negative perceptions about themselves based on their HIV status. Examples are self-exclusion from services and opportunities, perception of self, social withdrawal, overcompensation, fear of disclosure (Siyam'kela, 2003:14). Similar to the concept is the emic view of stigma (Weiss, 1993:1273). *Associated stigma* involves examples of stigma that result from association with someone living with, working with or otherwise associated with people living with HIV and AIDS (Holzemer *et al.*, 2007:547). Nyblade *et al.* (2003:34) refer to it as secondary stigma, meaning those related to or closely

associated with the infected person such as their spouses, children, family members, as well as care givers.

Holzemer *et al.* (2007: 550) grouped outcomes of stigma under the categories of general health, violence, poor quality of life and reduced access to care. Kruger *et al.* (2009:28) indicated stigma as a major barrier to HIV and AIDS care. Stigma related to HIV and AIDS contributes to delays and/or absence of diagnostic testing, lack of timely access to health care, and hesitance to disclose information to partners, family, friends or employers (Klein *et al.*, 2002:53). A relatively high percentage of individuals had not disclosed their HIV status to their sexual partners because of stigma and fear of their partners' reactions (Nachega *et al.*, 2005:200; Major & O'Brien, 2005:420). Among PLHA in South Africa, those who experienced stigma or discrimination were less likely to disclose their HIV status to their sexual partner, and non-disclosure was associated with transmission risk behaviour (Simbayi *et al.*, 2007:29). Greeff *et al.* (2010:475) found that perceived HIV stigma had a significantly negative and constant impact on life satisfaction for people living with HIV. Research suggests that stigma and discrimination reduces the impact of prevention programmes, inhibits treatment take-up and adherence, exacerbates the psycho-social effects of HIV infection and reduces the quality of life of people living with HIV and AIDS (Parker & Aggleton, 2003:19). HIV-related stigma, however, goes beyond individuals' experiences and affects the whole family and demonstrates that the stigma associated with HIV and AIDS has a substantial impact on family identity, relations within the family and within broader social networks, and behaviour related to coping with and reducing the associated distress (Li *et al.*, 2008:434).

4 Research Methodology

A qualitative holistic multiple case study design (Yin, 2009:59) and interpretive description approach (Thorne, 2008:50) was used.

4.1 Research setting

The study was conducted in Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district (urban), and Ganyesa as part of the Bophirima district (rural), in the North West Province, South Africa. In both settings the people speak mostly Setswana. The lifestyle in both settings are characterised by poverty and high unemployment rates.

4.2 Research method

Two phases characterize the research method through which this study was conducted.

4.2.3 Phase 1: A holistic multiple case-study of the community-based HIV stigma reduction intervention with PLHA and their partners

4.2.3.1 Sample

The population in this phase of the study was made up of two groups of people: PLHA and their partners living in the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district (urban) and in the Ganyesa district (rural) of the North West Province, South Africa. For PLHA purposive sampling (Thorne, 2008:90) was conducted. The following inclusion criteria were used: Diagnosed with HIV for at least 6 months; above 18 years of age; able to communicate in Afrikaans or English and Setswana; open and willing to share their experience in an in-depth interview and willing to be recorded on a digital recorder. Ten (9 females, 1 male) PLHA from the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district (urban) and eight (5 females, 3 males), from Ganyesa as part of the Bophirima district (rural) were identified, (n=18).

For partners of PLHA, snowball sampling (Burns & Grove, 2009:356) was used to identify the partners of the PLHA. Each PLHA was invited to bring a partner if they were actively involved in a relationship. The following inclusion criteria were used: a person living or sharing life with a PLHA or being married to them; above 18 years of age; able to communicate in Afrikaans or English and Setswana; open and willing to share their experience in an in-depth interview; willing to be recorded on a digital recorder. Few of the PLHA however, were in relationships at the time. Two (2) partners from the Potchefstroom sub-district which is part of the Dr Kenneth Kaunda district (urban) were included (2 males) and two (2) female partners from Ganyesa as part of the Bophirima district (rural) (n=4).

4.2.3.2 Data collection

Ethical approval was obtained from the Research Committee of the School of Nursing Science, as well as from the Ethics Committee of the North-West University, Potchefstroom Campus, NWU-00011-09-A1. Permission to undertake this programme was obtained from the Department of Health of the North West Province. A relationship with the community existed due to several community engagement projects. Participants were approached through health care settings, as well as Non-Governmental Organizations (NGO's). Nurses and health care workers were used as mediators to link the research assistant and researcher with the prospective participants. A private, interruption-free and comfortable venue for the intervention was arranged for both the urban and the rural settings. During the first contact with prospective participants, the research assistant explained the objectives of the research, ensured that they know what was expected of them and what kind of data would be collected, as well as that they were able to withdraw at any stage. Informed consent was obtained from each participant. Transport to venues was available for participants, as well as a light meal. Appointments were confirmed a day before the intervention.

4.2.3.3 The HIV stigma reduction intervention

Prior to the intervention all PLHA attended a workshop on their own about understanding HIV stigma, identifying their personal strengths and to manage disclosure in a responsible manner. This was intended to prepare them for future HIV disclosure. The workshop was presented by two facilitators, a non-infected and an infected person, trained beforehand to present the workshop. The underlying tenets of the intervention were: 1) to increase knowledge of HIV stigma and coping with it, 2) equalizing the relationship between PLHA and their partners; and 3) to empower them to handle HIV stigma through a community project with other partners. The workshop was presented by means of focused presentations, followed by activity-based group discussions involving both PLHA and partners at the same time. The intervention included a three-day workshop and a one month community project by the PLHA and partners for other partners in their community. Day one focused on sharing information on understanding HIV stigma and how to cope with it. The second day focused on

building a bridge between the knowledge and understanding they have gained and how to use it constructively in planning an HIV-stigma reduction community project with other partners in the community. This was followed by one month to conduct the project in the community. During this month the researcher and research assistant acted as facilitators. The third day of the workshop took place after the month-long project to evaluate the implementation of the project with other partners in their community. A project report was presented by the participants to invited stakeholders from the community and the researchers and they evaluated the presentation on this last day of the intervention.

The case study method was used to collect data during the five weeks intervention. The case record consisted of: the training manual and presentations; naive sketches that each participant wrote at the end of each workshop day. Two statements had to be completed: *“I experienced the first day of the workshop as ...”* and *“I feel ...”* Field notes were written during and at the end of every workshop day by the facilitators. The written project report and its evaluation also formed part of the case record.

4.2.3.4 Data-analysis

Data obtained from the case record was analysed using document analysis and looking for pattern matching, explanation building and cross-case synthesis (Yin, 2009:136).

4.2.4 Phase 2: Qualitative interpretive exploration and description of the lived experience of PLHA and their partners during and after the community-based HIV stigma reduction intervention

4.2.4.1 Sample

The same participants described under phase one was used for phase two.

4.2.4.2 Data collection

In this phase data were collected by means of in-depth interviews with both PLHA and their partners. The open-ended questions were discussed beforehand with experts, were adjusted and evaluated in practice. For the PLHA the question was: *“How did you experience the workshop and project with your partner and others in the group?”* For the

partners: “*How did you experience the workshop and project with your partner and others in the group?*” Appointments were made with participants beforehand and the initial informed consent was confirmed. The interviews took place in the setting most convenient and private for the participants. Communication techniques as mentioned by Okun cited in Botma *et al.* (2010:226) e.g. reflection, summarization, probing etc. were utilised. Participants were informed about the use of a digital recorder and that partial confidentiality and anonymity would be maintained throughout the process. Field notes were recorded noting the things the researcher heard, saw, felt, experienced and thought during the interview (Botma *et al.*, 2010:217).

4.2.4.3 Data analysis

The interviews were transcribed and manually analysed using the open coding technique of Tesch (1990), as discussed by Creswell (2009:186). The researcher got a sense of the whole, listed the topics as codes and turned them into categories and themes. An independent co-coder was used to analyse the data using a work protocol. Consensus discussions were conducted to come to an agreement about the coding, categories and final themes.

5 Trustworthiness

The researcher ensured rigour, using the model of Lincoln and Guba (Krefting, 1991:214). Truth value was assured by prolonged engagement during the intervention and interviews with participants. The researcher is part of a multidisciplinary research team. She consistently reflected on her experiences during the research through writing field notes and having discussions with study leaders. Triangulation of sources and investigators increased credibility. Saturation of data and a dense description of the research allowed for applicability. There is an audit trail and the possibility for a step-wise replication of the research is possible. A co-coder participated in data analysis. This ensured consistency. Neutrality was ensured through the audit trail, triangulation of sources and investigations and reflexivity.

6 Results

The results of this study focus on the case study description of the intervention, as well as the findings from the in-depth interviews. The urban as well as rural contexts were analysed and no real differences were noticed during the analysis. The discussion focussed on the whole. Specific mention is made in cases where differences were noted.

6.1 Phase 1: Findings from the holistic multiple case study

The findings focus on both PLHA and partners' experiences during the workshops and projects and are enriched by quotes of the participants.

6.1.1 Day one of the intervention

The purpose of this day was to get PLHA and their partners to understand HIV stigma, how to cope with it, and to build on and improve their relationships. From the naive sketches of the PLHA both urban and rural groups experienced that they gained knowledge about HIV stigma: "I have learned many things...today has taught me something in my life that I didn't understand". They felt empowered to reach out to others: "I am prepared to talk about this sickness without fear" and "I can teach other people about that stigma". A participant mentioned seeing strength in him/herself: "I experience PLHA are very strong and is not the end of the world". Participants felt that it was easier to accept their illness and stigma: "To be affected and stigmatised is not the end of the world or life". They learned that the experience of stigma can change: "...and how to change stigmatising" and "I have already changed my mind". They mentioned a mind shift filled with hope and happiness, as well as greater awareness: "Open my mind, I was in the darkness now I am in the lightness"; "Happy because I learn more"; "This workshop was amazing because I have noticed so many things I didn't know". They felt gratitude: "I thank God to give a mind to listen and open my ears to something special to me". They were proud of themselves: "I am so proud of myself" and felt a sense of belonging: "I feel like being one of them".

The partners of the PLHA of both urban and rural groups had similar experiences. They also mentioned gaining knowledge about HIV stigma and a change in attitude towards

PLHA: “They have opened up my eyes about stigma. I learned things that I did not know, care, sympathy and love”; “How to handle the people living with this stigma” and “I will help my girlfriend”. It empowered them to cope better: “How to cope with the situation”; “...how to promote your living style to a better one. Felt they could teach others about acceptance: “I am going to be able to teach other people to accept themselves”. They felt that the intervention added value to their life: “It is something valuable that will benefit me in the future.” They also experienced a new mind shift: “I consider it is educative and enlightening to my life”. The partners also felt encouraged to act: “To open our mind so that we can spread the message to the community”. They felt encouraged to seek help: “I have learned more about if you are depressed there are some people we can seek for help and support”. They took responsibility for their health: “To take care of ourselves and others around us”.

6.1.2 Day two of the intervention

The second day focused on building a bridge between knowledge of HIV stigma and coping skills and how to use it constructively in a visible HIV stigma reduction project with other PLHA and their partners in the community through activating their own leadership in social change. PLHA experienced this day as difficult, but in the end felt more empowered by the knowledge: “I worked hard but at the end I see where I am going to”; “It was so difficult today but I understand the way to organise the campaign but it is not easy.” They now felt they had the knowledge to act against HIV stigma: “I discovered many things and I am very educated. I am going to be able to unite partners.” They felt that they could be leaders in the community to reduce HIV stigma: “I see that I can be a leader and have my partner in this workshop”. The PLHA expressed specific feelings of self-confidence: “I believe I am smart” and experienced pride: “I feel that the knowledge has made strong. I am happy to begin doing something, making the project work”. The partners of PLHA felt empowered to encourage others: “Encouraging people in the community and to support other partners” and “I will be able to encourage people to support their partners”. They gained knowledge and wanted to repair relationships: “I discovered many things and I am very educated. I am going to be able to unite partners”; “Thank our facilitator to open our mind so that we can spread the message to the community”.

6.1.3 The projects done by both the urban and rural groups.

The urban group presented their project, “Remove the Label”, in a portable classroom at a local school, in Ikageng, Potchefstroom. The aim was to build a community of partners who will talk freely about HIV stigma. Through psycho-drama they demonstrated different types of stigmatisation to increase understanding and have partners stop labelling others, and to accept and support their own HIV positive partners. The event was managed by two partners and three PLHA. Sixteen (16) people were reached: Five partners, nine community members and two councillors. The sixteen attendees expressed their gratitude, but could also express their own experiences of stigmatisation. The rural group worked on a door-to-door project, “Coming Together and Working Together”, in one ward in Ganyesa as part of the Bophirima district (rural), with the aim of changing the community’s attitudes towards stigma, unite partners and encourage them to live freely together through improved communication. The two partners, with the support of two PLHA, reached five other partners. The group managed to visit seven houses of which they found partners in five. The partners were excited about the talk that was given to them in their own homes. They had the opportunity to express their own experiences of being stigmatised.

6.1.4 Day three of the intervention

Day three focused on the report-back by the participants regarding the execution of the project, as well as the evaluation by the researchers and important invited stakeholders from the community. The urban group experienced difficulty in recruiting partners, but recognised that it is important: “It was hard to get partners but we got them and learnt many, many things about the project.”; “How to deal with partners is not easy but if you want something you can do it.”; “Our community is in need to know more information.” They initially found it difficult to talk in front of others, but gained confidence: “It was not easy to talk in front of the people but now I am not afraid of the people or others in the community.” The urban group also expressed their intention to continue with projects in the community until they are satisfied that the people understand HIV stigma and change attitudes. They realized they should have invited people on time. Lack of transport and some passivity of group members made it difficult, but they reported that persistence and perseverance led to the success.

Both the PLHA and the partners experienced planning the door-to-door campaign in the rural area as a challenge, but they felt they achieved their goal and felt proud about it: “I thought it is going to be difficult. When we started to plan it was difficult but at the end we achieved what we wanted.” Presenting the project to the research team made them nervous: “I was a little bit nervous because it was the first time doing a presentation, so I had to stay focused in future and learn more on how to do these things”. Both the PLHA’s and the partners in the rural group felt proud about the project and more comfortable and encouraged that they could achieve their goal. The group members were strengthened by the workshop that motivated them to go ahead. The group felt that the door-to-door project was easy to do because they visited people in their homes in their own privacy. During the evaluation of the project the group expressed their intention to continue the project until they are satisfied that the people understand stigma and have changed their attitudes.

6.2 Phase 2: Findings from the in-depth interviews:

The purpose of the in-depth interviews with PLHA and their partners was to get an in-depth understanding of their lived experiences after having been part of the workshops and the project with other partners in their community to reduce stigma. The themes found during analysis of first the PLHA followed by their partners will be discussed with references to quotes from the in-depth interviews to enrich the discussion.

6.2.1 Findings from the in-depth interviews with PLHA

Five themes were identified from the findings of interviews with PLHA.

Theme one: Gained knowledge about HIV stigma and how to cope with it during the intervention

During interviews PLHA verbalized gaining knowledge about HIV stigma and how to cope with it: “I didn’t know about stigma but from the workshop I know more about the meaning of the word stigma, I only know the word HIV.”; “But in the workshop I experienced how to cope and what is stigma. Now I can educate people about it and how to deal with it.” They learned that stigma is powerful: “Stigma is a powerful social weapon that discriminating” and comes in different ways: “Like a sign or just gossiping

or labelling another person". During the intervention the participants experienced a shift from not feeling good about themselves to feeling better about themselves: "When I hear that I have HIV, I didn't feel well, I feel bad and I don't want to stay with the people but at the workshop they tell more things to disclose and I see that I'm still person and strong to do more things."

Theme two: PLHA became aware of the painful experiences of HIV stigma

PLHA shared painful experiences of stigmatisation: "...it's so painful when you tell someone you trusted and he turns you down"; "I felt ashamed"; "...they start to point fingers and gossip"; "being with people and isolate yourself from other"; "...you feel neglected".

Theme three: The intervention and project promoted support and human dignity

During the workshop and project the PLHAs learned what support is: "They give me support."; "All these people in the project respect each other, they hug each other and don't laugh at each other." They also learned how to be supportive and to support others: "It's nice to talk to PLHA that feels in the dark about it and I am able to give them advice that HIV doesn't mean the end of the world". The PLHA experienced the intervention as a safe and supportive environment where they learned to disclose without rejection: "We didn't judge each other, and there was openness, it felt like a blanket that keeps you warm, we all sharing the same problem". Leaving and returning back home was painful: "...and if I go home I feel the pain again". The support gave them strength and freedom: "I've been motivated", "I have some wings and flying out away, I've been brave that I can disclose it"; "I become happy and grateful".

Theme four: Improve self-image and self-acceptance

During the workshops and project PLHA regained their self-image: "I'm strong to do more things". They also realized that they can have meaningful lives: "...got hope in that sense you feel you accepted yourself and you can live long". They experienced more self-acceptance: "I learned to accept myself, others will accept you and you will feel free."; "We can be HIV positive without stigma".

Theme five: The intervention and project was initially difficult but empowered people to reduce stigma in the community to establish change and experience meaning

PLHA felt the initial fear to disclose: "...I was so afraid of, so scared to talk but after we attended the workshop I learned a lot, so I'm not afraid to talk about it". They verbalized that to plan the project was difficult: "It was so difficult to find the partners because they were always blaming their partners"; "...the problem is most of the fathers do not like to know about the HIV". However, they experienced success with their actions: "With the partners' door-to-door project we teach the people about HIV stigma, people stay and ask us questions. Then that people are happy because they say they don't know that we teach them." Another PLHA said: "For the first time before I disclose I stand in front of the people and teach them about HIV stigma and stop with the labelling". They felt happy because they gained knowledge: "We feel happy because they teach us something we didn't know, how you can speak about this disease, now it gave us strength to talk freely." The intervention empowered them to break through internal personal prisons: "I have a painful heart, staying alone and not want to stay with the person and the workshop teach me more things and me myself I was free because I can tell anybody"; "When I was talking, I was still feeling scared, but as it went, I felt free, and my heart opened up". PLHA verbalized that the workshop and project empowered them to help reduce stigma in the community: "My experience is to go far teaching people about that stigma and to go another places teaching the people about this in [the community]." They started to dream: "I want to open a house for the poor and stigmatised". Some PLHA's reached out on their own into the community: "I go to the clinic to talk to people...I spoke over the radio about HIV stigma...I got calls from different people about partners...I was going to the prison after they were calling me to go and visit them". PLHA felt motivated to educate the community: "It is important to me, if we reach more people, stigma will reduce in the community, people will rush to the clinics, they will not fear to go to the clinics because of stigma."

6.2.2 Findings from the in-depth-interviews with the partners

Five themes were identified from the in-depth interviews with the partners.

Theme one: Gained knowledge about HIV stigma and this led them to become leaders to empower others

They gained knowledge about stigma during the workshop and project: “Yes I didn’t know anything”. They expressed pride with their success: “I was very proud that I got that knowledge to teach the community.”; “I am able to encourage people to go and test and share my knowledge to them.” The project helped them to move from fear, to act and to be proud about their achievement: “At the time when we were going door-to-door and we had to teach people in their homes it was nerve-wrecking. I was happy to see that because if we had more of this, we will really end up with peace in the world as people with HIV.” They found it a life-changing experience: “It was life changing and felt like I was now in the light and it was the first hearing about stigma”

Theme two: Became aware of the painful experience of PLHA when stigmatised

The partners felt the pain of PLHA: “I was feeling just like them (PLHA), it was painful. This pain is that when they spoke and each one stood up and talked about the way people mistreated them.” They felt empowered through the knowledge they gained and felt determined to act against HIV stigma: “I feel proud and I feel an educated person and that it has really brought more insight to me. I can take everything that I have learnt and go out there and tell people to stop stigmatizing people with HIV.”

Theme three: Partners became united with PLHA and exchanged loneliness for support

Partners expressed that during the intervention and the project they became united with PLHA in the aim to reduce HIV stigma: “I experienced that we got together, the community as well as PLHA, and we got to teach them about stigma and that PLHA are just like any other person who is living with any other illness.”; “At the project I experienced that when a person lives with this illness and you have a partner, don’t point fingers, you should come together and fight this together”. Support from others in the project took the place of loneliness: “It was the support I got from the people I did the project with because they had the courage to stand in front of the community and say that they were HIV positive” and “I thought I was alone so now I experienced that when I go in the community I shouldn’t be afraid to talk to people about HIV”. They did not only feel supported, but also felt the ability to support other people in the community: “I felt like I was even more proud because people with this illness also came out because they were scared and they had no one to talk to so now they had her to run to and talk to her about this”.

Theme four: Partners became empowered to disclose their own status without fear and shame

Seeing their HIV positive partners disclose their status empowered them to disclose their own positive status without fear and shame: “That as a person living positively you shouldn’t fear saying that you are ill and hide it from people”. They felt less shame and were willing to disclose their own HIV positive status: “Sometimes when I was around others and they talked about people with AIDS I used to be ashamed and leave the room, but now I am able to talk to them and tell them that we can live with AIDS and take our medication”.

Theme five: Acceptance of self and joy that the community is willing to learn

They indicated that they have learned self-acceptance: “It taught me to accept myself and whatever obstacles and challenges that come my way to be able to face them”. They experienced joy to see willingness in the community to change: “I felt so happy to see the community willing to learn and accepting this”.

7 Conclusions

The urban and rural contexts were very similar in the case study and the in-depth descriptions of PLHA and partners. The findings of both the case study and the in-depth interviews validate the fact that the intervention was successful, based on what the participants reported. Both PLHA and partners expressed that they had initially limited understanding of the meaning of HIV-stigma and that they gained knowledge about stigma. They indicated that they learned to cope with HIV stigma. During the intervention both groups became aware of the painful experiences that stigma causes PLHA, and partners become aware how they hurt PLHA when they stigmatise. Partners realized that they needed to change their attitudes. In general a better relationship was established between PLHA and partners, but also in the group as a whole. Sharing these experiences during the intervention united PLHA and partners, increased their knowledge on HIV-stigma and coping, enhanced relationships between them, established support amongst members and decreased their feelings of loneliness.

Hope, dignity and pride of PLHA was restored and partners felt they could cope better and teach others about accepting PLHA. It even gave partners more freedom to disclose their own status. Both PLHA and partners experienced the planning of the project as difficult, but learned that when they work together with persistence and perseverance it can be achieved. Leadership was activated within themselves. They experienced pride and joy when they saw the change their action sparked in the community. They expressed a feeling of being empowered to reduce HIV stigma in their community.

8 Limitations

A limitation of the study could be the number of partners. Not all the PLHA in this study had a partner and the number of partners could not be increased because this intervention was part of bigger study, also involving children, family, friends, spiritual leaders and community members. Even with the small number data saturation was achieved.

9 Recommendations

The content and method used to implement the programme seems to be effective and need not be changed. The fact that this group was mainly Setswana-speaking could be a reason why no differences between urban and rural groups were noted. It could, however, be meaningful to add some cultural discussions. This study has the potential to be used for long-term monitoring studies of HIV-stigma reduction interventions and to evaluate change over time in PLHA and their partners, as well as other groups. This intervention could be included in educational programmes offered in health care settings or NGO's to nurses, health care workers and volunteers to get more people trained in HIV stigma reduction programmes.

10 References

- Alonzo, A. & Reynolds, N. 1995. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social science & medicine*, 41(3):303-315.
- Anglewicz, P. & Chintsanya, J. 2011. Disclosure of HIV status between spouses in rural Malawi. *AIDS care: psychological and socio-medical aspects of AIDS/HIV*, 23(8): 998-1005. doi: 10.1080/09540121.2010.542130
- Apinundecha, C., Laohasiriwong, W., Cameron, M.P. & Lim, S. 2007. A community participation intervention to reduce HIV/AIDS stigma, Nakhon Ratchasima province, northeast Thailand. *AIDS care: psychological and socio-medical aspects of AIDS/HIV*, 19(9):1157-1165. doi: 10.1080/09540120701335204
- Botma, Y., Greeff, M., Mulaudzi, M. & Wright, S. 2010. Research in health sciences. Cape Town: Heinemann.
- Brown, L., Macintyre, K. & Trujillo, L. 2003. Interventions to reduce HIV and AIDS stigma: What have we learned? *AIDS education and prevention*, 15(1):49-69. doi: 10.1521/aeap.15.1.49.23844
- Bunn, J.Y., Solomon, S.E., Varni, M.A., Miller, C.T., Forehand, R.L. & Ashikaga, T. 2008. Urban-Rural differences in motivation to control prejudice toward people with HIV/AIDS: The impact of perceived identifiability in the community. *The journal of rural health*, 24(3):285-291. doi: 10.1111/j.1748-0361.2008.00170.x
- Burns, N. & Grove, S.K. 2009. The practice of nursing research: appraisal, synthesis and generation of evidence. 6th ed. St. Louis, Mo: Elsevier Saunders.
- Creswell, J.W. 2009. Research design. London: SAGE.
- Goffman, E. 1963. Stigma: Notes on the management of spoiled identity. Englewood Cliffs, N.J.: Prentice-Hall.
- Greeff, M. 2009. A comprehensive community-based HIV stigma reduction and wellness enhancement intervention. (SANPAD research proposal, 15 September 2009. Reference number 09/15). (Unpublished).
- Greeff, M. & Phetlhu, R. 2007. The meaning and effect of HIV/AIDS stigma for people living with AIDS and nurses involved in their care in the North-West Province, SA. *Curationis*, 30(2):12-23. doi: 10.4102/curationis.v30i2.1066
- Greeff, M., Phetlhu, D.R., Makoe, L.N., Dlamini, P.S., Holzemer, W., Naidoo, J., Kohi, T.W., Uys, L. & Chirwa, M.L. 2007. Disclosure of HIV/AIDS status: Experiences and perceptions of persons living with HIV/AIDS and nurses in five African Countries. *Qualitative health research*, 18(3):311-324. doi: 10.1177/1049732307311118

Greeff, M., Uys, L.R., Holzemer, W.L., Makoe, L.N., Dlamini, P.S., Kohi, T.W., Chirwa, M.L., Naidoo, J.R. & Phetlhu, D.R. 2008. Experience of HIV/AIDS stigma of PLWA and nurses involved in their care from five African Countries. *African journal of nursing and midwifery*, 10(1): 78-108.

Greeff, M., Uys, L.R., Wantland, D., Makoe, L., Chirwa, M., Dlamini, P., Kohi, T.W., Mullan, J., Naidoo, J.R., Cuca, Y. & Holzemer, W.L. 2010. Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: A longitudinal study. *International journal of nursing studies*, 47:475-486. doi:10.1016/j.ijnurstu.2009.09.008

Heckman, T.G., Somlai, A.M., Kalichman, S.C., Franzoi, S.L. & Kelly, J.A. 2008. Psychosocial differences between urban and rural people living with HIV/AIDS. *The journal of rural health*, 14(2):138-145. doi: 10.1111/j.1748-0361.1998.tb00615.x

Heijnders, M. & van der Meij, S. 2006. The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, health & medicine*, 11(3):353-363. doi: 10.1080/13548500600595327

Holzemer, W.L., & Uys, L.R. 2004. Managing AIDS stigma. *Journal of social aspects of HIV/AIDS*, 1(3):311-324.

Holzemer, W.L., Uys, L.R., Makoe, L., Stewart, A., Phetlhu, R., Dlamini, P., Greeff, M., Kohi, T.W., Chirwa, M., Cuca, Y. & Naidoo, J. 2007. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of advanced nursing*, 58(6):541-551. doi: 10.1111/j.1365-2648.2007.04244.x

Klein, S.J., Karchner, W.D. & O'Connell, D.A. 2002. Interventions to prevent HIV-related stigma and discrimination: Findings and Recommendations for public health practices. *Journal for public health management and practice*, 8(6):44-53.

Krefting, L. 1991 Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy*, 45(3):214-222. doi: 10.5014/ajot.45.3.214

Kruger, A., Greeff, M., Watson, M.J., Fourie, C.M.T. 2009. Health care seeking behaviour of newly diagnosed HIV infected people from rural and urban communities in the North West Province of South Africa. *Africa journal of nursing midwifery*, 11(2):28-45.

Li, L., Wu, Z., Wu, S., Manhong, J., Lieber, E. & Lu, Y. 2008. Impacts of HIV/AIDS stigma on family identity and interactions in China. *Families, systems & health*, 26:431-422. doi: 10.1037/1091-7527.26.4.431

Link, B.G. & Phelan, J.C. 2001. Conceptualising stigma. *Annual review of sociology*, 27:363-385.

Major, B. & O'Brien, L.T. 2005. The social psychology of stigma. *Annual review of psychology*, 56(1):393-421. doi: 10.1146/annurev.psych.56.091103.070137

Manyedi, M.E. 2007. Coping with stigma by women whose partners died of AIDS. Potchefstroom: North-West University (NWU). (Thesis – PhD.).

Manyedi, M.E., Greeff, M. & Koen, M.P. 2010. Implementing a programme for coping with stigma for women whose partners died of AIDS: A case study. *Africa journal of nursing and midwifery*, 12(1):39-51.

Nachega, J.B., Lehman, D.A., Hlatshwayo, D., Mothopeng, R., Chaisson, R.E., & Karstaedt, A.S. 2005. HIV/AIDS and antiretroviral treatment knowledge, attitudes, beliefs and practices in HIV-infected adults in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndromes*, 38(2):196-201.

Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoe, L., Dlamini, P., Phetlhu, R.D., Chirwa, M. & Kohi, T. 2007. Urban and rural differences in HIV/AIDS stigma in five African countries. *African journal of AIDS research*, 6(1):17-23. doi: 10.2989/16085900709490395

Nyblade, L., Pande, R., Mathur, S., Macquarrie, K., Kidd, R., Banteyerga, H., Kilonzo, G., Mbwambo, J. & Bond, V. 2003. Disentangling HIV and AIDS stigma. International Center for research on women.

Obermeyer, C.M., Baijal, P., & Pegurri, E. 2011. Facilitating HIV disclosure across diverse settings: A review. *American journal of public health*, 101(6):1-22. doi: 10.2105/AJPH.2010.300102

Parker, R. & Aggleton, P. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine*, 57:13-24. doi: [http://dx.doi.org/10.1016/S0277-9536\(02\)00304-0](http://dx.doi.org/10.1016/S0277-9536(02)00304-0)

Sallar, A.M. & Somda, D.A. 2011. Homosexuality and HIV in Africa: An essay on using entertainment education as a vehicle for stigma reduction. *Sexuality & culture*, 15:279-309. doi: 10.1007/s12119-011-9094-1

Sengupta, S., Strauss, R.P., Miles, M.S., Roman-Isler, M., Banks, B. & Corbie-Smith, G. 2010. A Conceptual model exploring the relationship between HIV stigma and implementing HIV clinical trials in rural communities of North Carolina. *North Carolina medical journal*, 71(2):113-122.

Siyam'kela. 2003. Siyam'kela measuring HIV/AIDS related stigma: A report on the fieldwork leading to the development HIV/AIDS stigma indicators and guidelines. Policy Project, South Africa: Centre for the Study of AIDS. University of Pretoria; United States Agency for International Development; Chief Directorate: HIV, AIDS, TB, Department of Health. <http://www.csa.za.org> Date of access 13 Nov. 2013.

Simbayi, L.C., Kalichman, S.C., & Strebel, A. 2007. Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. *Sexually transmitted infections*, 83:29–34. doi: 10.1136/sti.2006.019893

Statistics S.A. 2011. Midyear population estimates. <http://www.statssa.gov.za/Publications/statsdownload.asp?PPN=P0302> Accessed 03012012.

Taylor, C. 2001. Scaling up for Social Development. Sussex: ILEIA. United Nations Development Programme (2000) Human Development Report 2000. New York: UNDP.

Thorne, S. 2008. Interpretive description. California: Left coast press.

Turan, J.M., Bukusi, E.A., Onono, M., Holzemer, W.L., Miller, S. & Cohen, C.R. 2011. HIV/AIDS Stigma and refusal of HIV testing among pregnant women in rural Kenya: Results from the MAMAS study. *AIDS and behavior*, 15:1111-1120. doi: 10.1007/s10461-010-9798-5

UNAIDS. 2012. UNAIDS report on the global aids epidemic. <http://www.unaids.org> Accessed 13112013.

Uys, L., Chirwa, M., Kohi, T., Greeff, M., Naidoo, J., Makoe, L., Dlamini, P., Durrheim, K., Cuca, Y., Holzemer, W.L. 2009. Evaluation of a health setting-based stigma intervention in five African countries. *AIDS patient care and STDs*, 23(12):1059-66. doi:10.1089/apc.2009.0085

Valerian, J., Derlega, B.A., Winstead, K.G., Julianne, S. & William, N. 2002. Perceived HIV-related stigma & disclosure to relationship partners after finding out about the seropositive diagnosis. *Journal of health psychology*, 7(4):415-432. doi: 10.1177/1359105302007004330

Varas-Diaz, N., Serrano-Garcia, I. & Toro-Alfonso, J. 2005. AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. *Qualitative health research*, 15(2):169-187. doi: 10.1177/1049732304272059

Weiss, R.A. 1993. "How does HIV cause AIDS?" *Science magazine*, 260(5112):1273-1279. doi: 10.1126/science.8493571

Wu, S., Wu, Z., Ling, L., Coa, H., Yan, Z. & Lil, J. 2008. A brief HIV stigma reduction intervention for service providers in China. *AIDS patient care and STD'S*, 22(6):513-518. doi: 10.1089/apc.2007.0198

Yin, R.K. 2009. Case study Research. 4th ed. London: SAGE.

Zeelen, J., Wijbenga, H., Vintges, M. & de Jong, G. 2010. "Beyond silence and rumor: Storytelling as an educational tool to reduce the stigma around HIV/AIDS in South Africa". *Health education*, 110(5):382-398. doi: 10.1108/09654281011068531

SECTION D: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

1 Conclusions

The urban and rural context was very similar in the case study and the in-depth interviews of PLHA and partners during and after the intervention between the rural and urban communities. From the literature it is clear that there is no consistency in whether urban or rural communities experience the most HIV stigma. The fact that no difference was experienced can be due to the cultural context of the study, with most of the participants being Setswana speaking in both urban and rural areas included in study. The findings of both the case study and the in-depth interviews validate the fact that the intervention was successful based on what the participants reported. Both PLHA and partners expressed that they initially had limited understanding of the meaning of HIV-stigma and that they gained knowledge about stigma. The main focus was on really understanding what HIV-stigma is and how to cope with it. Their awareness of how powerful stigma is, increased. During the intervention both groups became aware of the painful experiences that stigma causes PLHA, and partners became aware how they hurt PLHA when they stigmatise. Partners realized that they needed to change their attitudes. In general a better relationship was established between PLHA and partners, but also in the group as a whole. Sharing these experiences during the intervention united PLHA and partners. PLHA and partners learned how to be supportive towards one another and how they could disclose without rejection. Their loneliness became less.

In general, the PLHA experienced improvement in their self-image and self-acceptance. The intervention empowered them to break through interpersonal prisons and truly experienced freedom. Partners on the other hand added the dimension of losing their fear and started acting within their own communities. This took the place of their experiences of loneliness.

Hope, dignity and pride of PLHA was restored and partners felt they could cope better and teach others about accepting PLHA. It even gave the partners freedom to disclose their own status during the intervention.

Both PLHA and partners experienced the planning of the project as difficult, but learned that when they work together with persistence and perseverance it can be achieved. Leadership was activated within themselves and pride and joy was experienced when they saw the change their action sparked in their own community. They expressed being empowered to reduce HIV stigma in their community.

The aims of the study were achieved, namely to reduce HIV-stigma experiences of PLHA and stigmatisation by partners. They became much more understanding. The tenets that the intervention was planned on held, in that knowledge on HIV stigma and coping with it was increased, relationships were restored and equalized, and personal leadership was activated to take control in making a difference in their own communities through stigma reduction actions.

The way the intervention was planned to first prepare PLHA for disclosure before taking them into the group will always be essential, as this could be a traumatic experience. Having a person living with HIV and one not infected as facilitators sets the tone of acceptance and equal relationships. Having the PLHA and their partners together in the group facilitated the improvement of their relationships. The content in interactivity led to change in stigma experiences as well as stigmatizing behaviour. The project truly empowered participants to act against HIV-stigma in their community and take back control instead of isolating themselves. Dignity and pride was restored.

2 Limitations

A limitation of the study could be the number of partners. Not all the PLHA in this study had a partner and it could not be increased because the intervention formed part of bigger study, also involving children, family, friends, spiritual leaders and community members. The therapeutic nature of the intervention also does not allow for large numbers. The sample size thus could not be determined beforehand.

3 Recommendations

The content and method used to implement the intervention should not be changed to achieve the same positive results. It could, however, be meaningful to add some cultural discussions into the workshops. Extending research to include different cultural groups in different provinces could be meaningful.

This study has the potential to be used for long-term monitoring studies of HIV stigma reduction interventions and to evaluate change over time in both PLHA and their partners, as well as other groups.

This intervention could be included in educational programmes offered in health care settings or NGO's to nurses, health care workers and volunteers to get more people trained in HIV stigma reduction programmes.

APPENDIX A: ETHICAL APPROVAL FOR THE STUDY



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

Prof M Greeff

Ethics Committee
Tel +27 18 299 4850
Fax +27 18 293 5329
Email Ethics@nwu.ac.za

2009-03-31

ETHICS APPROVAL OF PROJECT

The North-West University Ethics Committee (NWU-EC) hereby approves your project as indicated below. This implies that the NWU-EC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: A Comprehensive Community-Based HIV Stigma Reduction and Wellness Enhancement Intervention																
Ethics number:		N	W	U	-	0	0	0	1	1	-	0	9	-	A	1
		Institution			Project Number						Year		Status			
Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation																
Approval date: 30 March 2009								Expiry date: 29 March 2014								

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principle investigator) must report in the prescribed format to the NWU-EC:
 - annually (or as otherwise requested) on the progress of the project,
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviation from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-EC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - withdraw or postpone approval if:
 - any unethical principles or practices of the project are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,
 - the required annual report and reporting of adverse events was not done timely and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof MMJ Lowes
(chair NWU Ethics Committee)

Prof HH Vorster
(Chairman: NWU Ethics Committee: Author)

APPENDIX B: CONSENT TO BE A RESEARCH PARTICIPANT

THE NORTH-WEST UNIVERSITY AND VRIJE UNIVERSITEIT AMSTERDAM

CONSENT TO BE A RESEARCH SUBJECT

A COMPREHENSIVE COMMUNITY-BASED HIV STIGMA REDUCTION AND WELLNESS ENHANCEMENT INTERVENTION

1 PURPOSE OF THE STUDY

A team of researchers from various disciplines of the North-West University and the Vrije Universiteit, Amsterdam are conducting a study on a comprehensive community-based HIV stigma and wellness enhancement intervention in the North West province, South Africa. You are being asked to participate in this study because you are a person living with HIV or a person living and working close to a person living with HIV.

2 PROCEDURE

If you agree to be in this study the following will occur:

- A set of questionnaires will be completed by you prior to a workshop.
- If you are a HIV positive person an in depth interview will be conducted with you at the beginning of the research and you will be expected to join an initial two day workshop followed by six workshops with people living and working close to you.
- If you are a person living or working close to a person living with HIV you will be expected to join a two day workshop followed by a project that you will be involved in for a month that will be evaluated during a further one day session.
- After the workshops interviews will be conducted with you asking you about you experiences during the intervention.
- This will be followed by questionnaires completed by you on a three monthly basis for four times during 2011.

3 RISK/DISCOMFORTS

As people living with HIV and people living and working close to such persons the HIV status of the person will be made known to all the people in the various groups. In the workshops you will be joined by other people similar to yours. Sharing experiences could be painful and uncomfortable. Some of your privacy might be lost during the intervention, however your data will be handled as confidential as possible. Your name will never be made known and no individual identifiers used in any publications resulting from the survey. Only the team of researchers will work with your data.

4 BENEFITS

By being involved in this research project will become knowledgeable about HIV stigma, learn to cope with the situation and become empowered to be leaders in the field of HIV stigma reduction. Your participation will help the researchers to develop a comprehensive community-based approach to reduce HIV stigma.

5 COSTS

There will be no cost to you as a result of your participation in the study.

6 PAYMENT

You receive no payment for participation. You will receive a meal and refreshments during the workshop days and will be transported to the site.

7 QUESTIONS

You can talk to Prof Greeff (project leader) or Poncho (research assistant) if you have any further questions concerning your consent. They can be reached at 018 299 2092.

8 CONSENT

You will be given a copy of this consent to keep.

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point.

Should you be willing to participate you are requested to sign below.

I.....hereby voluntarily consent to participate in the above-mentioned study. I am not coerced in any way to participate and I understand that I can withdraw at any time should I feel uncomfortable during the study. I also understand that my name will not be disclosed to anybody who is not part of the study, that the information will be kept confidential and not linked to my name at any stage. I also understand that I might benefit from the intervention. Should I experience any emotional discomfort I will be referred for counseling.

Date

Signature of the participant

Date

Signature of the person obtaining consent

APPENDIX C: EXAMPLE OF A NAÏVE SKETCH

Participant: Code: 201-1

I experienced this first day of the workshop as:

I experienced a lot in this workshop. How to cope with the situation you are facing. How to handle the people living with this stigma. I have learned more about if you are depressed there are some people we can seek for help and support. The other thing is how you can promote your living style to a better one. To take care of our selves and others around us.

I Feel:

More comfortable to meet someone that encourage me to go and spread the message to the community to reduce the pandemic of HIV/AIDS.

APPENDIX D: EXAMPLE OF A FIELD NOTE

FIELD NOTES FOR INTERVENTION - PARTNERS (Urban)

Day 1

Demographic Notes

Day 1 of Stigma intervention for partners of PLHA at an Urban site took place on 11 August 2010 in the Heimat building on the Potchefstroom Campus of the North-West University. The participants were eight (8) PLHA, all ladies with three (3) male partners. It was a cold day. The workshop commenced late (09H35) due to having to wait for some participants. Ultimately, the workshop kicked off with the eleven participants. The hall was quiet and conducive, with sufficient chairs and tables. The seating arrangement was circular to facilitate free communication and to avoid barriers between the facilitators and the participants. Two facilitators and a Master's student worked together with one presenting, the other one interpreting to both the participants and to the student.

Observational Notes

Participants (PLHA) looked excited with the mood of looking forward to the events of the day, although their partners looked worried, uncertain of what was going to happen. However, the atmosphere was that of commitment, freedom, openness and friendliness. All the ladies (PLHA) participated actively, sharing their knowledge and understanding of stigma, experiences of stigmatisation, as well as sharing the different types and dimensions of stigma. The partners demonstrated commitment, but with minimal participation, only talking when they were asked directly. They also pledged their support for their partners. The discussion was led by the ladies, who also shared their partners' experiences. Throughout the activities of understanding stigma and their experiences of stigmatisation, the ladies talked on behalf of their partners. All their partners demonstrated humility, blended with a certain degree of shyness. It was obvious that they could understand to a lesser extent, hence interpreting was a major activity throughout. On the first day, most activities were manageable as the participants could follow and it mostly involved their experiences of stigmatisation and coping. They

especially enjoyed the coping exercises. What was not easy for them was the primary and secondary appraisal. The day went well and participants acknowledged it in their evaluation.

Personal notes

As the facilitator I was humbled by the commitment that the male partners demonstrated despite their quietness. Belonging to the same culture, one understands how difficult it could be for the male partners to commit themselves to support their partners, but these men were committed to supporting their partners. The facilitation of activities went smooth because they could share their experiences and understanding of stigma. They could associate with the types and dimensions of stigma and shared real experiences. The exercise on coping with stigma showed that most of them do employ positive coping mechanisms, though they were expressed in a superficial way. The facilitation was manageable on this day because participants were active and had rich stories to tell, even on behalf of their partners. The exercise that seemed difficult for them was the Stigma appraisal, which they undertook minimally. The events were summarised and they all acknowledged in their evaluation that they enjoyed the workshop.

APPENDIX E: SECTION OF AN IN-DEPTH INTERVIEW

NWU Transcripts

by Globosonic DFH

Respondent I think there's some people when you're, you're just speaking to them, you say, "Me, I'm positive." They don't take you like them. They say, "That one." They look after you and say, "That one is going to die," but I think it's not that; you can't not die because of you HIV positive.

Moderator Yeah, so it doesn't make a difference.

Respondent People, yes. Yes it doesn't.

Moderator Okay. Have you experienced that people have said that to you?

Respondent Lots of them.

Moderator Lots of them?

Respondent Lots of them, like my neighbors. I start to tell them "(INAUDIBLE) just look at me" and I have a friend. She explain to others that I'm positive and then that other one is going to gossip. With me they go around. "When you coming around?" They say, "That one is positive. That one (INAUDIBLE) is positive." I'm not her friend anymore. I just go to them and tell them, "When you positive, I'm like you, and me, I'm better because I know my status. You do you know your status?" She say, "No I don't." Now this time, she's coming to me. I must explain now positive people (INAUDIBLE) how we must do. I explain to them, I just go to them and I'm making a support group now in my.

Moderator Really?

Respondent In my community, yes.

Moderator Okay, so you helping people understand what it means.

Respondent Yes.

Moderator Okay, that's wonderful. You're like a teacher.

Respondent Yes.

Moderator And have you experienced that friends will tell other people about your status?

Respondent Yes.

Moderator Okay, can you tell me more about that?

Respondent (INAUDIBLE).

Moderator Okay, and in your support group, your other people—what kind of stories have people told you about their experiences of stigma?

Respondent I don't want to say. When you are positive, they just want to, when you positive “I can touch you?” I say, “Yeah you can touch me.” When you positive, you can't transfer the positive, transfer positive like through kissing me, or through touching me, or using a toilet. You just going to by blood transmittion, you see? Or by mother by getting, when the mother is pregnant when she's going to get a (INAUDIBLE) then you can get a positive like that. You understand (INAUDIBLE). I understand how is positive working.

Moderator Okay.

Respondent Most of them, they didn't know that how you get positive. And when you positive, it doesn't like say I'm sleeping around, and I'm prostitute or I was prostitute or you see. The other people, they taking us light. When you are positive they say, “That person was sleeping around and she was a prostitute.” No, it's not like that.

Moderator Okay.

Respondent Yes.

Moderator When people tell you these things, have you yourself in the past before you had all this knowledge, have you experienced those things that people say? You mentioned that sleeping around or prostitute? Can you tell me if there's any experiences like that?

Respondent I did experience it first. I did get that the clinics; then they tell us when you get (INAUDIBLE).

Moderator Okay. What did they tell you at the clinics?

Respondent At the clinics they tell me, no, when you positive it's when you sleeping around with different partners and then by blood.

Moderator Okay.

Respondent Yes, they tell me that.

Moderator Okay, and can you tell me a little bit about how you can (INAUDIBLE) at that time, how you felt when they spoke about that at the clinic?

Respondent I was feel so scared. I was just (INAUDIBLE) know how did I get positive? I didn't expect to be positive, but when I go to get my first (INAUDIBLE) Dr Tukerman say you positive and my child is also positive. I just went to the doctor to explain for me how did I get (INAUDIBLE) HIV. Then he explain for me, "Maybe you get it from your partner or by blood," because I was so sick, so sick. At the time I was pregnant. Then they take me to the ICU, and then they give me blood. Even now, I didn't know how did I get positive, by that blood or by my partner (INAUDIBLE).

Moderator So it's a big question?

Respondent Yes it's a big (INAUDIBLE). It's still a big question to me.

Moderator Okay, and I just want to ask a little bit more about your time in the clinic and the hospital. What was that experience like?

Respondent My time, at the hospital?

Moderator Yes.

Respondent (INAUDIBLE) I slept for a month at the hospital because I was bleeding and sweating. All my face was swollen and I was (INAUDIBLE). They said, "I sleep for a month so that you can get better," and they give me drips and they give me blood. They say my blood was low, and my CD4 was still (INAUDIBLE) My CD4 count was still (INAUDIBLE). Then when I starting to get ARVs I get better, and my CD4 count (INAUDIBLE).

Moderator Okay. Okay that's good, and not just how you felt physically when you were getting swollen. How did you fell inside?

Respondent (INAUDIBLE) so that now I'm feeling better because I go to support groups at the clinic. Every month, they tell us how you must feel when you are positive. You musn't get scared. You must tell other people how you feel and you must tell other people your status. It doesn't matter how they take it, (INAUDIBLE), you know I can explain to you, (INAUDIBLE) don't take light and just start to gossiping and to hate me. Yes, the other people was like that.

Moderator Okay. Have you experienced that?

Respondent Yes.

Moderator Other people gossiping about you?

Respondent Yes.

Moderator Okay. Can you tell me more about that?

Respondent (INAUDIBLE) that one that was doing; that was my close friend. (INAUDIBLE) going to separate me, go that side, I'm going to that side, (INAUDIBLE) start to hate me and don't want to go with me (INAUDIBLE) anywhere that she want to go, (INAUDIBLE) and she say, "What will the people say when I go with people like her with HIV." I say,

“You started to gossip to me, because you are my close friend. How the people can know if you didn't tell them?”

Moderator And how did that feel?

Respondent It was sore (INAUDIBLE) so sad, so sad (INAUDIBLE).